From scared to prepared?

Identifying important areas in the educational preparation of nursing students with respect to palliative care

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Masteroppgave ved Det medisinske fakultet

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Tittel og undertittel: Fra redd til forberedt? – ***identifisering av viktige områder innen lindrende behandling sykepleierstudenter har behov for å lære om gjennom utdannelsen***

Sammendrag:

Formål:
Identifisering av viktige områder sykepleierstudenter trenger kunnskap om innenfor lindrende behandling. Overordnet mål er at denne informasjonen kan bidra til å utvikle strategier for optimalisering av sykepleierutdanningen.

Litteraturgjennomgang:
Oppgaven gir bakgrunnsinformasjon i forhold til økt etterspørsel etter kompetanse innen lindrende behandling. I tillegg gis en oversikt over eksisterende litteratur angående innhold og evaluering av ulike utdanningsprogram.

Metode:
Studien har et kvalitativt, eksplorativt design med elementer av kvantitativ metode. Datainnsamling ble foretatt gjennom en spørreundersøkelse med ett åpent spørsmål. Undersøkelsen ble besvart av 140 respondenter fra tre ulike grupper, sykepleierstudenter, sykepleiere og lærere som underviste i lindrende behandling. Det ble utført innholdsanalyse av innsamlet data med utgangspunkt i Crabtree og Miller ”Editing analysis style”.

Funn:
Følgende syv ulike områder med 25 tilhørende underkategorier ble identifisert som viktige i forhold til lindrende behandling:
Relasjonskompetanse, symptomhåndtering, smertehåndtering, generell kunnskap om lindrende behandling, kontekstuelle forhold, psykisk helse og døden som fenomen. Det ble identifisert et essensielt område som i stor utstrekning ikke ble gjort rede for i sykepleierutdanningen: Betydningen av personlige egenskaper og erfaring og holdninger til død og døende.

Konklusjon:
Det er behov for et felles utdanningsprogram innen lindrende behandling for implementering i sykepleierutdannelsen i Norge. Et slikt utdanningsprogram bør gjennomføres gjentatte ganger i løpet av utdanningen, og ta for seg de ulike områder identifisert i studien. Det bør være fokus på at egenskaper ved studenten er spesielt viktige, som personlige erfaringer, holdninger til døden og dødsangst.

Nøkkelord: Lindrende behandling, sykepleierutdanning, sykepleierstudenter, døden.

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Title and subtitle: From scared to prepared? ***Identifying important areas in the educational preparation of nursing students with respect to palliative care***

Abstract:

Aim of the study:
Identify important areas in palliative care for nursing students to learn about through the nursing education. From this the over all aim is to give information that can provide strategies for optimizing nursing education.

Literature review:
The thesis gives background information on how nursing students feel unprepared to carry out palliative care. There is also an account of the increased demand for competence in palliative care, as well as an overview of existing literature on the content and evaluation of different educational program with respect to palliative care.

Method:
The study has a qualitative, explorative design with elements of quantitative methods. Data was collected through a survey with an open-ended question. The survey was answered by 140 respondents from three different respondent groups; nursing students, nurses and teachers of palliative care. A content analysis of the data was performed drawing on principles articulated by Crabtree and Millers ”Editing analysis style”

Findings:
The following seven different areas with 25 related subcategories were identified as being of importance for nursing students to learn about: Interpersonal skills, symptom management, pain management, knowledge on palliative care, contextual conditions, mental health issues and the concept of death. An area identified as a vital issue, but not addressed well in nursing education was that of how students’ personal qualities and experience with death and dying impact on their preparedness to nurse palliative patients.

Conclusion:
There is a need for a common educational program in palliative care to be implemented in nursing education in Norway. Such a program should be introduced repeatedly throughout the course of the nursing education, and should address the areas identified in this study, Special attention should be paid to issues in the students themselves, in regards to personal qualities, attitudes toward death and death anxiety.

Key words: Palliative care, nursing education, nursing students, death.

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Fredrikstad June 2nd

Camilla Hardeland

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Prologue

As a young 1st year nursing student back in 1996, very inexperienced and somewhat naive, I had eight weeks of student placement at a nursing home. I enjoyed this very much, and started working there in weekends after the practice period was over. One of the patients suffered from aphasia. He was very frustrated when we didn't understand what he tried to express, but he never gave up trying. Consequently I used a lot of time trying to understand him, and we got to know each other well. I came to work one day, and they told me he was in bed with pneumonia. His condition deteriorated rapidly and the next time I was at work he was terminally ill. I was asked to spend the shift in his room, looking after him at all times as they expected him to die during the day.

I was scared. Terrified.

I had never seen anyone die before, and I had no idea what to expect. Would he be in pain? What should I say and do? Would I know when he was about to die? But most of all, I didn't want him to die. The past months we had made a connection, we had many laughs, and I cared a lot for him. Entering this situation was extremely difficult, and it made such a deep impression on me that I never forgot it. I remember everything, how scared, sad and terrified I felt and my struggles to try to look confident in this situation, which I thought was expected of me.

Twelve years later, I was in the process of deciding what to write about in the masters' thesis. One of the teachers at the local nursing school shared information about how student evaluations repeatedly told them that the students felt unprepared to carry out palliative care. He expressed the need for a study within this area. I immediately thought of my first experience with a dying patient. What could have made me feel ready to enter this situation without feeling so scared and unprepared? On the basis of this notion and the reading of a number of research articles discussing the area, I decided to explore the issue of how to make nursing students feel more prepared to carry out palliative care. This study is the result.

1. Introduction

1.1 Background and significance of the study

This study identifies strategies that can be used for improving nursing education in the area of palliative care. Palliative care involves the nursing of patients with incurable diseases and short expected lifespan, for elaboration of this see section 1.1.1. In this study nurses, nursing students and teachers in palliative care were asked in a survey about important areas for nursing students to learn about through the nursing education with respect to palliative care. Based on findings from the survey and existing literature, suggestions are made that can assist in the development of an educational program in palliative care to be implemented in nursing schools in Norway. This program should address issues concerning how the students should care for both the patient and themselves, in regards to dealing with death and dying. In the following sections in this opening chapter I will give an account of the term "palliative care" and how this is defined and made use of in the study. I will also discuss why such a study is necessary given the background and rationale for the study. On the basis of information given in this introduction, the research problem and research questions are outlined in section 1.1.6 page 15.

1.1.1 Definition of palliative care

The term palliative care is defined in very different ways in different settings. The term can be used in a broad way to include chronic diseases and patients who might have a long expected lifespan, but are in need of pain relief, and it can be used for dying patients in the very last phase of life. In defining palliative care for this study I started out with the definition given by the World Health Organization. The English definition, which varies slightly from the Norwegian, is the following:

”An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”[1]

(WHO, 2009)

For the basis of this study, this definition was too extensive when defining palliative care to the respondents in the survey. The definition should not give any kind of answers to the respondents on what palliative care imply, The definition used by WHO could potential bias the data as it implies priorities within palliative care. I needed to define the patient group for the respondents and further determine who was in need of palliative care by this definition. As the definition would be included in an intensive information letter it was imperative that the term was short, concise, and easily understood.

The definition given by WHO is broadly referred to, both internationally and in Norway. The Norwegian Cancer Society, The Norwegian Medical Association and public documents from the government all make use of this definition. Thus, it was essential that the respondents could readily relate to any modifications to the standard definition.

When defining the term palliative care to the respondents, I wanted to restrict any possible expansions of the definition. For instance, I wanted patients with chronic disease to be excluded by the definition. Simultaneously, I wanted to avoid the possibility of providing the respondents with any pre-conceived notions on what

[1] Norwegian version: “Palliasjon er aktiv behandling, pleie og omsorg for pasienter med inkurabel sykdom og kort forventet levetid. Lindring av pasientens fysiske smerter og andre plagsomme symptomer står sentralt, sammen med tiltak rettet mot psykiske, sosiale og åndelige/eksistensielle problemer. Målet med all behandling, pleie og omsorg er best mulig livskvalitet for pasienten og de pårørende. Palliativ behandling og omsorg verken framskynder døden eller forlenger selve dødsprosessen, men ser på døden som en del av livet.”

palliative care could imply. The purpose of the study is to gain the respondents' opinions on this exact subject. Taking these considerations into account, I decided to define the term palliative care to the respondents as follows:

"Active treatment, caring and nursing of patients with incurable diseases and short expected lifespan".[2]

This modified use of WHO's definition was a methodological choice to ensure the answers reflect the actual opinions of the respondents.

1.1.2 Assertions about the problem of discussion

Having defined palliative care, I will at this point make some general assertions about the situation for nursing students, and the challenges they face in the course of the education with respect to caring for palliative patients. Subsequently I will give background information elaborating on why these assertions are viewed as valid and legitimate.

Nursing students face demanding circumstances when addressing the needs of dying patients. The students are expected to focus on communication, consideration and empathy in addition to medical knowledge necessary to provide for the patients' extensive physical needs.

The importance of being well prepared to carry out this complicated kind of nursing seems obvious. However, I believe there is a difference between <u>being</u> prepared and <u>feeling</u> prepared. The students might have been prepared before entering this situation in regards to knowledge and practical skills. This does not necessarily mean that they feel prepared when encountering dying patients. It can be difficult to deal with thoughts and feelings regarding death and dying for both the patient and the student.

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[2] Norwegian version, as given in the information letter: "Aktiv behandling, pleie og omsorg av pasienter med en inkurabel sykdom og kort forventet levetid".

This will add an extra challenge for students when aiming to provide satisfactory level of nursing care. Despite such challenges, this field of nursing education is underdeveloped in both content and quantity (Kwekkeboom, Vahl, & Eland, 2005). As a result of this deficit, nursing students express that they feel insecure and unprepared when encountering patients in need of palliative care. It is this that prompts the need for my study – how to educate nursing students so that they are prepared for palliative care in a way that makes them feel prepared.

Bjørk & Solhaug (2008) suggest different ways of legitimating the need for a project. I will use three of the ways they identify to justify the need for this study.

- Challenges in clinical practice
- Existing literature
- Political agenda

(ibid)

1.1.3 Challenges in clinical practice

Challenges in clinical practice are often a basis for research. Situations arising from practice aspire to questions that can develop into areas interesting for different research projects (ibid). My own experience of feeling unprepared as a nursing student, as described in the prologue, was one initial reason why I questioned the preparation of nursing students with respect to palliative care. Further, there is anecdotal evidence that supports the fact that nursing students feel unprepared to carry out palliative care – even if it is not research based. For example, I was asked to explore this issue by a local nursing school. They had identified a gap where there was a need for improvements in the nursing education. Student evaluations and the teacher's experiences established reasons to believe that the students felt nervous and unprepared when encountering palliative care patients. These evaluations and experiences are viewed as clinical practice hence legitimate reasons for initiating the study.

1.1.4 Existing literature

Existing literature can also provide the rationale for a study. Scientific articles and text books can give background information that leads to discussion about a subject found suitable to explore further (Bjørk & Solhaug, 2008). When turning to literature seeking for explanations for the issue in question, I found that the assertions made by the nursing schools were supported by existing literature. Kwekkeboom et al (2005) found that a great many studies reach the same conclusion: nursing students express that they feel nervous and unprepared when encountering patients in need of palliative care. This is supported by numerous research articles (Arber, 2001; Cooper & Barnett, 2005; B. Ferrell, Virani, Grant, Coyne, & Uman, 2000; Mallory & Allen, 2006).

It has been difficult to find scientific articles dealing with palliative care and nursing students in Norway. Searches made of the databases CINAHL, Medline, Embase, ERIC, the Cochrane library, SweMed and NORART have resulted in few relevant articles of studies carried out in Norway. It has been necessary to turn to studies carried out in other countries to find background information on this subject. The lack of studies in this field in Norway, underlines the need to do a study under Norwegian conditions. Even though the search for scientific articles yielded limited results in Norway, I make the assertion that what is found in international studies in regards to inadequate preparations of the students also applies to Norwegian conditions. This assertion is supported by the experiences of the Norwegian nursing school previously mentioned.

1.1.5 Political agenda

Subjects on the political agenda and governmental documents can be a pointer to what areas are viewed as important political issues in society (Bjørk & Solhaug, 2008). In the overall plan for nursing education, one of the aims of the education of nurses is to give the students competence in how to ”relieve suffering and help the patient to a dignified death” (Kunnskapsdepartementet, 2008). This objective presents

an extensive and demanding task to inexperienced students. Simultaneously, demand for competence in palliative care within the nursing profession continues to rise in accordance with the increasingly larger patient group. Prognosis tell us that the need for palliative care for patients in the last stage of life will increase significantly over the next few years (Helse-og-omsorgsdepartementet, 2006a). Palliative care is for all patients with incurable diseases, but cancer patients constitute the dominant group among palliative patients. Approximately 20 000 cancer patients are in need of palliative care each year. ”Nasjonal strategi for kreftområdet 2006-2009” states that the prevalence of cancer will increase by 25 % within 2020. Furthermore demographic changes project that the number of elderly people over the age of 80 will double over the next 35 years (Helse-og-omsorgsdepartementet, 2006a). The combined increase of cancer patients and an aging population will place increased stress for health services focusing on palliative care. In response to this demand, ”Omsorgsplan 2015” from Helse- og omsorgsdepartementet stated that the government will enhance the competence and strengthen the facilities for palliative care (Helse-og-omsorgsdepartementet, 2006b). Increased demands for competent palliative caregivers will consequently impact on the nursing education in Norway in the immediate future.

1.1.6 Research problem and research questions

In the previous section I have described two overall issues:

- The increase of demand for competence in palliative care in the years to come
- The future care givers; today’s nursing students, express that they feel insecure and unprepared when encountering palliative patients

Combined these issues indicate the need for this study aiming as it does, to assist in making nursing students feel better prepared to carry out palliative care, hence increasing the competence of future palliative care givers.

On the basis of this background information the following research problem is formulated:

”What are the important areas in palliative care for nursing students to learn about through the nursing education?”

Research questions within this problem are the following:

1) What do nurses, nursing students and nursing teachers say about the important areas for nursing students to learn about in palliative care?

2) What are the differences and/or similarities between what the different groups of respondents say about the important areas for nursing students to learn about in palliative care?

3) What are the differences and/or similarities between the findings in this Norwegian study and findings in similar studies abroad?

4) In what way can findings from this study give implications for practice with respect to palliative care?

1.2 The aim of the study

The aim of this study is to identify important areas for nursing students to learn about through the nursing education with respect to palliative care. Findings from this study can inform guidelines for nursing schools in Norway on what to emphasize in the education of nurses with respect to palliative care. From this the overall aim of the study is to give information that can provide strategies for optimizing nursing education and in this way help nursing students to be and feel better prepared to carry out palliative care.

1.3 Outline of the thesis

Having established the background and rationale of the study, the composition of the thesis is as follows:

The introductory chapter (1) gives background information of why this study is necessary, describes its aims and objectives and gives a literature review. The following chapter (2) introduces the choice of design and method and describes how the study has been carried out. It also deals with limitations of the study and ethical considerations. The analytical process is described in chapter 3. The findings are presented in chapter 4. In chapter 5 the findings are discussed in relation to the research questions, with a summary and conclusion in chapter 6.

There will be red threads to follow throughout the thesis. The use of theory is implemented in all parts of the study and will be presented accordingly where in use in each chapter. The choice of theory is based on methodological choices as well as emerging from findings. According to Malterud, (2003) this is an inductive approach to the use of theory. Additionally there will be a red thread on how to ensure rigour in all parts of the study.

Throughout the thesis I will make comparisons to an American study by White, Coyne and Patel (2001). I have modeled on this study when designing my study, but with alterations where it seemed necessary for enhancing the quality of my study and extending the original study by White et al (ibid). In this study 56 registered nurses were asked: “what do you wish you had been taught in nursing school about caring for dying patients and families?” Each respondent listed 1-5 responses and a total of 160 responses were received from this question. The initial data was combed for common themes and cross referenced against existing literature in order to structure twelve different categories the nurses wished they had learned about in nursing school. The secondary study asked 750 nurses to rank these twelve categories by importance from 1-12 (1=most important, 12=least important). The result of the study is a list of the areas, ranked by importance (ibid). When making comparisons to White et al, I have chosen to use the same terms to avoid confusion of what I’m

comparing. White et al (2001) use the term ”core competencies” where I have chosen the term ”area”. They use the term ”end-of-life care” where I have chosen to use ”palliative care”. To make it easier to read and compare, I will use the terms ”areas” and ”palliative care” when discussing both studies.

1.4 Literature review

In order to elucidate the problem it is relevant to map out the content of the nursing education in regards to palliative care. In this literature review I will also include educational programs that deal with palliative care but with different target groups than nursing students. Examples of this are further education in palliative care and courses intended for nurses who work with palliative care on a daily basis. From these different educational programs one can assess what are generally regarded as important areas in palliative care and what nursing students should learn about through the nursing education. In addition it is necessary to review evaluations of different educational programs to see what has impacted students and their ability to carry out palliative care. From this general conclusions can be drawn regarding the impact of educational programs on the students. This approach then allows for the findings in this study to be compared against the findings in existing literature. Previous to mapping out the content and evaluation of different educational programs, I will give an overview of the process of searching for literature.

1.4.1 The search for literature

I have used several different databases when searching for literature. Examples of this are CINAHL, MedLine, PubMed, EMbase, ERIC, The Cochrane Library, SweMed and NORART. CINAHL, with a particular focus on nursing sciences has been the primary source. Key words varied somewhat between the different databases, but the main key words were the following: ”nursing students”, ”nursing education”, ”palliative care”, ”terminal care” and ”death education”. For examples of search history, se appendix 3. After having an overview of the literature from these searches,

new, more specific key words were searched, like for instance ”death anxiety”. Quite a few articles were found through references from other articles. The reason for this is that I have aimed to use primary sources whenever possible. Secondary sources has been used to a limited degree when necessary.

The following sections give an overview of the content and evaluations of different nursing education programs in regards to palliative care.

1.4.2 The content of the education in Norway

In Norway the Ministry of Education and Research gives an overall plan for nursing education that aims to give guidelines and regulations for the content and organization of the education. However, this overall plan speaks in very general terms. While each nursing school is bound to this plan, individual nursing schools are at liberty to organize their teaching in each subject area. When it comes to palliative care the overall plan says, as mentioned in the introduction, that students must be able to ”relieve suffering and help the patient to a dignified death” (Kunnskapsdepartementet, 2008). It is then up to each nursing school what means are used to reach this goal, both in terms of practice and theoretical tutoring. I reviewed curriculums in ten different nursing schools in Norway, both schools that are a part of this study and other randomly chosen schools. Palliative care was uniformly not emphasized in the curriculum. Course descriptions were vague, often listing ”palliative care” among an extensive list of other subject areas. It is difficult to determine what is actually being taught in the different nursing schools under the heading ”palliative care.” Among the ten nursing schools, only one school had a specific course in the theme palliative care. This two-week long course addressed the following subjects:

- Values and thinking within hospice philosophy
- What is palliative care?
- Lifetime perspective and understanding the last phase of life
- Soothing of pain, suffering and comfort
- Fatigue and the consequences for everyday life

- Nursing and a dignified death
- Loss, grief and hope
- Ethical considerations linked to the framework conditions for hospice philosophy

(Lovisenberg Diakonale Høgskole, 2008)

A review of a Nordic textbook in palliative care intended for nursing schools show that the topics presented is focused around the following subjects:

- What is palliative care?
- The patient and the relatives
- Organization and funding issues
- Pain and pain therapy
- Other symptoms and conditions

(Kaasa, 2007)

The previous was an overview of what was found in Norway in regards to the content of the education. I have also searched international literature to survey different educational programs and will elaborate on this in the following. Most of this literature is either American or British, this is not intentional, but searches in databases gave most relevant studies from these countries.

1.4.3 The content of the education internationally

Dickinson, Clarke and Sque (2008) have evaluated how the nursing education in the UK historically has developed in regards to curriculum in palliative care. They state that a shift has occurred from a curriculum dealing primarily with practical skills to increased emphasis on communication and interaction, both with patients and their relatives. At the same time there has been an increasingly larger amount of literature and lessons regarding palliative care. In spite of the fact that more attention is given to the area of death and dying in nursing schools, it is still an area where the content of the education is said to be minimal (Dickinson, 2007).

In the US there has been a national educational project called End-of-Life Nursing Education Consortium (ELNEC) where the aim was to improve the competence of nurses in regards to palliative care. An educational program focusing on nursing students was developed. Based on research done by the American Association of Colleges of Nursing (AACN) the curriculum was focused around nine core areas;

- Nursing care at the end of life
- Pain management
- Symptom management
- Cultural consideration in end-of-life care
- Ethical/legal issues
- Communication
- Loss, grief and bereavement
- Achieving quality care at the end of life
- Preparation for and care at the time of death

(B. R. Ferrell, Virani, & Malloy, 2006)

These defined core areas have since then been guiding lines for education in palliative care in the US, both when it comes to development of special educational programs and also for the choice of topics in textbooks (B. Ferrell, Virani, Grant, Vallerand, & McCaffery, 2000; Thompson, 2005)

The Palliative Care Quiz for Nursing (PCQN) was developed in 1995 to measure nurse's knowledge of palliative care. Respondents were asked to identify 20 statements as "true", "false" or "I don't know". This assisted in identifying concrete practical problems that nurses giving palliative care face. The themes generally correspond with the core areas from the ELNEC program (Ross, McDonald, & McGuinness, 1996)

Likewise Kenny (2001) shows how a 13 weeks educational program had positive results in increasing nursing students knowledge- and competence level. The areas in the program here also overlapped with the previously mentioned core areas.

Other educational programs such as the Tool Kit for Nurturing Excellence at the End-of-Life Transition (TNEEL) incorporated different terminology. They used six main topics referred to as ”connections” (communication, roles, and relationships), “comfort” (goals and pain and symptom management), “ethics,” “grief,” “well being” (hope and psychosocial care), and “impact” (the epidemiology and “economics” of dying) (Haylock, 2003). These terms also correspond well with the nine core areas defined by AACN, as pointed out in the article.

Registered nurses with experience in palliative care can be important contributors to assess what nursing students should learn about in nursing school in regards to palliative care. In the previously mentioned study by White et al (2001), nurses were asked what they wished they had been taught in nursing school about caring for dying patients and their relatives. Results showed that what was mostly missed in the education were how to talk to patients and families about dying.

After reviewing a number of different educational programs I discovered that several studies focus on a topic received little discussion in textbooks on palliative care. This is the issue of death anxiety in the students. Facing death is a frightening experience. Most nursing students are young, potentially having little to no experience relating to dying people and their relatives. The importance of taking death anxiety into consideration was emphasized in several studies, but rarely addressed as an issue in the specific educational programs. I will give an overview of different studies that focus on death anxiety to give a picture of why this is an important issue to consider.

According to Dickinson (2007) death anxiety issues are shaped during students initial educational programs, and it is essential that students recognize and confront their own reactions to death in training An educational program should therefore focus on letting the students reflect on their own attitudes and concerns about death. To do this, several different approaches have been described. Examples include visualizing

ones own death, written statements on personal experiences around death, reactions to educational programs, role-plays and conversation groups. According to Dickinson (2007) studies that evaluate end-of-life programs have yielded differing results regarding degree of death anxiety after completing an end-of-life program. For instance is it described by Lockard (1989) how the students who attended a specific educational program about death and palliative care had a significantly lower degree of death anxiety than the ones who didn't attend this program. The measurements were done right after the program was completed, one month later, and then again one year after completion.

Kurz and Hayes (2006) studied nurses attending an ELNEC program. Degree of death anxiety was measured before the program (pre-test), immediately after the program (T1), six months later (T2) and one year later (T3). Results showed a small increase in death anxiety at T1. At T2 the reports were a significantly decrease in death anxiety, and at T3 there was the same degree of death anxiety as in the pre-test. The author explains the result by saying that through confrontation the nurses have an increase in death anxiety (T1), but in the long run the program will pay off and the nurses have a more reflective attitude towards death, which will decrease death anxiety. However, the results are not long lasting, and the author concludes that it is necessary to repeat the program to optimize the effect.

According to Kurz and Hayes (2006), Johansson and Lally explored the effect of a one-month program in palliative care. Results showed that students in the first part of the education had a higher degree of death anxiety after attending the program than before. This was not the case with students in the last part of the education. The authors concluded that clinical experience with palliative care has an impact on death anxiety (ibid).

In addition to death anxiety, I will draw attention to another issue described as crucial when it comes to nursing education and palliative care. Mallory (2003) points out the importance of timing when it comes to teaching palliative care. To teach palliative care early in the education is problematic as students lack a larger body of knowledge

on which to apply the training. That being said, students are more likely to be flexible regarding attitudes toward death and dying and less shaped by previous experiences that might have caused incorrect attitudes and assumptions that may develop later in their education.

After having mapped out the content of different educational programs, there is still one question left. What is the actual impact on the nursing students when they attend a program in palliative care? Does it make a difference? In order to make assessments about this I will give an overview of evaluations made of different educational programs in palliative care in the following.

1.4.4 Evaluation of different educational programs

Evaluations of the ELNEC program have shown predominant positive outcomes of attending the programs. Ferrel et al (2005) refers to the ELNEC-program as "extremely successful", and show significant improvements in the knowledge level in the students. Barrere, Durkin and LaCoursiere (2008) found that the ELNEC program had positive effect on the students attitudes towards palliative care. Two significant factors for attitude change after attending the program were identified: age, and previous experience with individuals who were dying. Younger students (age 18-22) and students with no previous experience with death, were most likely to positively change their attitudes toward care of the dying. The importance of integrating the ELNEC-program repeatedly throughout the nursing education was underlined. Thompson (2005) registered that nursing students who attended an elective course addressing palliative care issues had a 30 % improvement in comfort level regarding care of the dying.

Arber (2001) asserts the importance of an additional specific educational module in palliative care in the nursing education in Great Britain. Evaluations were made in such a palliative care educational module. In this study 1/3 of the students choose to attend the program. The rest of the students followed the regular nursing education program. The students who chose this particular program had 50 hours teaching and one

week of practice on a palliative unit. By the means of the above-mentioned Palliative Care Quiz for Nursing, the knowledge level was measured at all the students the first day, and at the last day. Results show in general a significantly higher knowledge level in the group that followed the program, compared to the rest of the students, but with some variety within the different areas.

Kwekkeboom et al (2005) evaluated an educational program entitled Palliative Care Companion Program. Students volunteering to attend the program were given a theoretical introduction to palliative care. They had the opportunity to spend time with dying patients who are lonely and without any family. The students aimed to make a connection to the patient without directly participating in the practical nursing issues. The concept implies that the students accept the role traditionally performed by a family member. This enables the students to develop a sense of safety when interacting with dying patients. An additional hope is to create an ongoing interest in palliative care resulting in the student independently seeking additional knowledge. The control group was evaluated using four different measurements. Demographics, knowledge level (PCQN), attitudes and concerns about palliative care were mapped out. The experimental group and the control group shared similar demographic backgrounds. The results showed significantly higher scores on knowledge level among the students who attended the program. More positive attitudes to palliative care were measured in the areas of nursing role and responsibility, the importance of interaction and communication and believing in palliative care as something more than medical treatment. In several different aspects of palliative care, the students had less concerns after completing the program.

As a summary the literature show increased knowledge levels and more positive attitudes in the nursing students after attending an educational program. It is however, important to be aware of the fact that these are all statistical measures that doesn’t say anything about whether the increased knowledge level makes the students feel more prepared to carry out palliative care. This introductory chapter has aimed to give an insight in what this study is about and why it is important. The following chapter will deal with how the study was planned and carried out, in regards to design and methods.

2. Research design and method

This study has a qualitative, explorative design with elements of quantitative methods linked to it. Data was collected through a survey with an open-ended question asking about the important areas for nursing students to learn about in regards to palliative care, see appendix IV. The answers were ranked by importance. Statistics were used to give an overview of the data, as I summed up the number of answers given in each area, as well as the rankings. This quantification of the data are presented in tables showing how many respondents listed each area, and the average ranking of importance connected with standard deviation. See appendix VI-VIII. The survey was answered by 140 respondents from three different respondent groups; nursing students, nurses and teachers of palliative care. In the following I will account for the reasoning behind the choice of design and method, and explain in detail the execution of the study.

2.1 The design of the study

This chapter is an elaboration of the above mentioned opening statement, that this study has a qualitative, explorative design with elements of quantitative methods linked to it. There are several aspects to consider when planning the research design of a study and I will give an account of the details in the chosen design for this study combined with a discussion of literature that can underpin this choice.

The research design is the overall plan for obtaining answers to the question being studied, including specifications for enhancing the study's integrity (Polit & Beck, 2008). The main issue is how to be able to address the aim of the study and the research questions. In this case how to, in the best possible way, be able to identify the important areas that nursing students need to learn about through the nursing education. I believe a qualitative approach is necessary to be able to do this. Qualitative methods emphasize an in-depth and holistic fashion, often investigating a phenomenon, using a flexible design (ibid). The advantage of a qualitative approach

is that you have detailed information on the issue under study, which increases the depth of understanding (Patton, 2002). A qualitative approach is necessary for two reasons: First, the identification of important areas in palliative care have to be based on what the respondents themselves feel are important, and not based on preconceived notions of the researcher. The aim is to have in-depth information about this issue, and qualitative data is consequently necessary. Secondly, when little is known about a field, it is more purposeful to use a qualitative approach (ibid). The fact that there is so little research done under Norwegian conditions supports the choice of using a qualitative approach.

There is, however, no reason to completely rule out the opportunity to make use of statistics and in this way quantify the data. The presentation of the collected data will be in the form of tables and overviews presenting how many respondents listed the different areas, and the connected rankings of the areas in terms of average and standard deviation. This as an addition to a thorough description of what the areas are about. This use of statistics when presenting the data can be viewed as a form of mixed-methods approach with an emphasis on the qualitative part of the study.

Sandelowski (2001) claims that there is a myth about qualitative research that real qualitative researchers do not count, and cannot count. She argues that whenever qualitative data are placed into categories, and the researcher find themes and patterns, they draw from the numbered nature of their analysis. In this way, counting is integral in the analysis process.

In general, there are several options as to which approach a study will undertake. Some studies are strictly qualitative or quantitative both in regard to design, sampling, data collection techniques or data analysis, but other studies will mix the different approaches in different parts of the study. According to Sandelowski (2000) qualitative and quantitative techniques can be used together and either remain distinct design components or be explicitly integrated. The two approaches can be regarded as equally important, or one can have higher priority than the other in the study. Sandelowski gives an overview on the different ways of combining the two

approaches, and highlights which approach has the higher priority. Examples can be the following:

- QUAL>quan
- QUAN>qual
- Quan>QUAL
- Qual>Quan>Qual

(Sandelowski, 2000)

My study involves both a qualitative and a quantitative approach. However, there is a clear emphasis on the qualitative approach, and the mixed methods approach can be described like QUAL>Quan. The qualitative part of the study has the highest priority by far, and the quantitative part of the study aims to add to the findings in the qualitative part. The reason the data is quantified in the first place, is because the use of tables that show rankings and how many of the respondents said this was important will give a very good overview of the findings and make it easier to see what is generally viewed as more important.

In White et al's (2001) study, there was a triangulation in choice of design. The first part of the study, which aimed to identify the different core areas, had a qualitative approach, whereas the second part of the study, which aimed to rank the importance of the core areas, had a quantitative approach. The purpose of the study is said to be "to determine end-of-life care core competencies and educational needs, and to describe the characteristics of the respondents". Which part of the study that has the higher priority is uncertain, but the mix of methods is in this order: Qual>Quan.

In addition to the distinction between qualitative and quantitative approach, it is also useful to classify the design from the purpose of the study, and the varying levels of explanation. If a study is meant to provide explanatory information, which this study is, there are different terms used to classify the study. The different purposes of a study include identification, description, exploration, explanation, prediction and control (Polit & Beck, 2008). This study has an exploratory design. An exploratory

design starts with a phenomenon of interest and investigates the full nature of this phenomenon. You seek to shed light on the various ways a phenomenon is manifested and on underlying processes (Polit & Beck, 2008). When identifying the different areas that are important for nursing students to learn about, I will not simply replicate the answers given by the respondents, but define the areas from what they are actually about. This way I aim to explain the underlying meaning and what the implications for practice might be. This is done in chapter three, that describes the analytical process.

To some extent this also has the design of a comparative study, but with a difference. Comparisons with White et al's (2001) study is made throughout the thesis. However, this is only possible in some parts of the study, as there are differences both in groups of respondents and data collection techniques.

2.2 Ensuring rigour

Different terms are used in qualitative studies on how to enhance the quality of the study. In quantitative studies, the terms validity and reliability are acknowledged as quality criteria. These terms refer to the degree to which interferences made in a study are accurate and well founded, whether a study's instrument measures what it is intended to measure, and the degree of consistency with which an instrument measures an attribute (Polit & Beck, 2008). According to Rice and Ezzy (1999) these questions have to some extent relevance to qualitative research also, but there are problems in applying it to qualitative research methods, and the terms need to be conceptualized differently. They described various techniques for ensuring rigour in qualitative research. Rigour is a term that addresses both the issues of validity and reliability as well as the role of the observer and the contextual setting of what they observe.

Rice and Ezzy (1999) suggest 6 different techniques for ensuring rigour:

- Theoretical rigour
- Methodological or procedural rigour
- Interpretative rigour and inter-rater reliability
- Triangulation
- Evaluative rigour: ethics and politics
- Rigorous reflexivity

I will give a brief overview of these different techniques as described by Rice and Ezzy (ibid) with some examples of how I have used them in different parts of the study. Further discussion of rigour is made throughout the thesis in each part of the study.

Theoretical rigour means that theory and concepts chosen in the study are consistent with the aim of the study. This includes the choice of method for addressing the research problem. I have justified the choice of design and method as well as the use of theory throughout the thesis.

Where theoretical rigour deals with the reasoning for choice of method per se, methodological rigour concerns the documentation of how the research was conducted. By explicitly accounting for the entire research process, from sampling strategy, data collection, analysis and findings, it is possible to assess whether the conclusions are well funded and trustworthy. I have addressed methodological rigour by describing in details the different stages of the research process, and exploring potential methodological problems throughout the study.

Interpretative rigour deals with the interpretations of the data as described by the researcher are valid and accurately representations of the understandings of the respondents. To ensure this, the researcher should show in detail how the interpretation was achieved, by including substantial parts of primary texts in the research report. I have attended to this by giving examples of interpretations in the analysis chapter (3), and including appendices that show raw data and how they have

been split and assigned to areas and subcategories, see appendix V. Because this is raw data, it has not been translated into English. I have also in the following given examples of potential differing interpretations and how and why I concluded to assign the statements to a specific area.

Inter-rater reliability concerns whether the interpretations made by the researcher would comply with others reviewing the research material. This can be ensured by making external peers, the respondents or other relevant audiences agree that interpretations and conclusions are accurate. According to Rice and Ezzy (1999) inter-rater reliability in qualitative research has been an issue of debate in terms of whether there can be said to exist one true meaning of a text, uninfluenced by the researchers beliefs and understandings. In my study the issue of inter-rater reliability have been addressed by discussing the interpretations with a co-student, a fellow research team and my supervisor.

Triangulation can involve the use of combination of different aspects of the research process. Examples of this are different methods, researchers, data sources and theories. In my study the triangulation factor is the combination of collecting qualitative data with the use of statistics for presentation of the findings. The quantification is adding to the qualitative data as a mean to give better overview of the findings.

When it comes to evaluative rigour, this deals with the ethical and political aspects of qualitative research. This involves, among other things, gaining the necessary ethics approvals and ensuring the confidentiality of the respondents. This is secured in my study by seeking advise from Norsk Samfunnsvitenskapelig Datatjeneste (NSD) before starting the study. The respondents are anonymous, but asked to state gender and age.

Rigorous reflexivity concerns the researcher as part of the setting, context and culture of the phenomenon of study. The researcher should give an account of their actions and their role in the research process, and subject these to the same crucial scrutiny as

the rest of their data. I have addressed the issue of reflexivity in a separate section in the analysis part of the thesis, see section 3.1.1 page 46.

2.3 The method of the study

The choice of method in this study is data collection through a survey with an open-ended question, see appendix IV. I will give an overview of the considerations made up to the point where this approach was considered suitable.

The choice of method, like the choice of design, was assessed in regards to the aim of the study and how to answer the research questions in the best possible way. The major types of data collection methods include self-reports, observation and biophysical measures. For qualitative research, the primary methods of collecting data are through self-report or observations. Self-report involves directly questioning people about the concerning issue (Polit & Beck, 2008), and is the choice of method in my study. There are a number of advantages in the method of self-report. The most efficient way of gathering information when we want to know what people think or believe, is to simply ask them about it (ibid). Observations cannot give the direct answer to our questions in the way that self-report can. Self-report can also give information that would be difficult to gather in any other way, for instance by gathering retrospective information about previous activities or events, or information about planned behaviors in the future. Opinions, values and attitudes can to some extent be interpreted through observation, but people's actions do not always indicate their state of mind. The method of self-report is consequently very good for capturing what people actually mean about the concerning issue. However, there are some limitations to this method. It is impossible for the researcher to know whether or not the respondent feel or act the way they say they do, or if they want to present themselves in the best possible way, conflicting with the truth (ibid). In my study however, I see this as a minimal problem, as the question asked is not of a kind that will set the respondent in a bad light if answered in a "wrong" way. There are no

”right” or ”wrong” answers in this survey, and I don’t think the respondents will feel forced to answer untruthful because they want to be viewed in the best possible light.

In addition to the type of data collection methods, a decision about methodological techniques and what kind of qualitative data to collect was considered. The detailed descriptions of the considerations made in this process, is a way to ensure methodological rigour. Different options were considered in regards to what kind of qualitative data I wanted to collect, like interviews. However, this study aims to identify areas important for nursing students to learn about through the nursing education and what I really wanted in this study was specific answers to that one question; What are the important areas in palliative care for nursing students to learn about? When reading White et als’ (2001) study, I found that they aimed to do exactly the same. The result of that study is a list of nurses’ end-of-life care core competencies, ranked by importance. I decided to model on, not replicate, this study. Alterations and improvements in regards to methods and analysis were made when necessary. The result of my study is a list of the important areas nursing students need to learn about through the nursing education, also ranked by importance. I believe the choice of modeling on White et al’s (ibid) study enhances theoretical rigour, as the aim of that study coincides with the aims of my study. White et al’s choice of method is a written survey with an open-ended question in the first part of the study, to be able to identify the core competencies. In the second part of the study, there is another written survey where these core competencies are ranked by importance. My study incorporates both parts of this study in one. The data are in the form of written responses to an open-ended survey. For a more detailed description of this, see the section on data collection (section 2.5) and data analysis (chapter 3).

2.4 Sampling

Respondents in this study are from three different groups; nurses, nursing students and teachers of palliative care. To choose these respondents, sampling strategies are vital. To ensure theoretical rigour, I have chosen to follow Patton’s guidelines for

purposeful sampling (Patton, 2002). According to Patton the different sampling strategies are possibly the main difference between qualitative and quantitative research. Where quantitative research usually has an emphasis on random sampling and a large number of respondents, qualitative research often has a limited amount of respondents, carefully chosen for the study. This is called purposeful sampling. Respondents are chosen on the fact that they are regarded as information rich, they have experience in the area of interest, and can be expected to give useful and rich information for the study. Patton (ibid) describes 15 different sampling strategies. It is possible to choose one strategy or combine different strategies when doing sampling.

The first sampling strategy was to find who can be the most information rich to answer what nursing students need to learn about through the nursing education when it comes to palliative care. In White et al's (2001) study, the respondents were registered nurses who work with palliative care on a daily basis. One can imagine that they have expert information on the topic, and are well suited to judge what the nursing students need to acquire of knowledge and skills to be prepared to carry out palliative care. On the other hand, the population of the study is nursing students, and it seems suitable to use students as respondents. They have first hand experience on what it's like to be a student, and what it is they actually need to know. In addition they know what the education contains and possible shortcomings in the education. It seems suitable to use both groups as respondents. In addition I have also used teachers in palliative care as respondents. Teachers have first hand knowledge and experience in both education and practice. This is an expedient combination when respondents are chosen from who is the most ”information rich”. Both nurses, nursing students and teachers are regarded as being able to provide valuable information and different aspects to the study, and together they can give a better answer to the problem than they can separately. By this use of multiple information sources, or what Rice and Ezzy (1999) describe as ”triangulation”, I contribute to ensuring rigour. Further on, I had a sampling strategy in the three different groups. I decided from what nursing schools the students and the teachers should be chosen, and from which institutions the nurses should be chosen.

The sampling strategy for the choice of nursing schools was ”maximum variation”. This is described by Patton (2002) as purposeful when the aim is to capture and describe the central themes that cut across a great deal of variation. By choosing maximum variation you can both catch the extremes as well as the different opinions on the topic. Possible patterns that come from a maximum variation strategy is of particular interest as it complies with a lot of people in a heterogeneous group.

To find maximum variation in the nursing schools, I considered the following factors: location, size and whether or not they had further education in palliative care at the school. Two schools were chosen. Within these schools 3rd year students were chosen as respondents. 1st and 2nd year students were thus excluded. This is because 3rd year students have more experience in both theoretical lessons and practical training from the school in regards to palliative care and is considered more information rich. All of the 3rd year students were asked to participate in the study.

When it comes to the teachers, the respondents were the ones that teach palliative care in the two chosen schools. Due to the limited amount of teachers who teach palliative care in each school, ”Snow ball sampling” was used in addition to have more respondents. Snow ball sampling is an approach that start out by asking key informants, in this case the teachers in charge of teaching palliative care, who else to talk to that is considered ”information rich” (Patton, 2002). Examples of this can be guest lecturers and teachers in other branches of study, with competence in palliative care. To be able to also reach these teachers, snowball sampling was considered the most purposeful sampling strategy.

When deciding on the choice of nurses, maximum variation was also the preferred sampling strategy. One can imagine that for example a nurse from community care and a nurse who work in intensive care might have different focus on what the students need to learn, and it would be interesting to catch as many aspects as possible of the matter. The respondents were chosen from four different parts of the health service; from a hospital, a nursing home, community care and a hospice. This way all the respondents in this group worked within the field of palliative care, but

they differed in the way this work was carried out. Consequently all the respondents were chosen from maximum variation in regards to location, but also in regards to the nursing role. In the hospital a ward for cancer diseases with a palliative unit was chosen. The nursing home chosen also has a palliative unit. The community care chosen has a special focus on palliative care, and has its own palliative team. In addition to the nurses at the hospice, this is considered to constitute a group of respondents with high competence in palliative care. On all of the locations, all the nurses were chosen as respondents. The only demographic data that was collected in the survey were gender, age and possible further education. Inclusion criteria were registered nurse and experience with palliative care in practice.

According to Polit and Beck (2008) there are no rules for sample size in qualitative research. The aim is to have data saturation, sampling to the point at which no new information is obtained and redundancy is achieved. In White et al's (2001) study, 56 nurses were used as respondents to find the important areas. In my study the number of nurses as respondents were somewhat the same, but in addition to nurses, there was an equal number group of nursing students. In addition some teachers were also respondents. As mentioned earlier, there are very few teachers who teach palliative care in each school, hence the limited number of teachers.

What follows is a schematic outline of the sampling as well as a demographic profile of the respondents.

Schematic outline of sampling:

Table 1

Choice of schools

School	Location	Further education in school
Small school	North, 9 000 inhabitants	No
Large school	South-east, 72 000 inhabitants	Yes

Table 2

Choice of students

School	Respondents (n)
Small school	21
Large school	39

Table 3

Choice of teachers

School	Teachers (n)	Teachers with further education (n)
Small school	2	0
Large school	6	2
Additional school	3	0

Table 4

Choice of nurses

Location	Nurses (n)	Nurses with further education (n)
Hospital – Oncology ward	22	2
Nursing home	19	4
Community care	12	0
Hospice	16	7

Table 5

Total number of respondents

Respondent group	Number of respondents (n)
Students	60
Teachers	11
Nurses	69
TOTAL	140

Table 6

Demographic profile of the respondents

Respondent group	Male (n)	Female (n)	Average age	Respondents with further education (n)
Students	8	52	28,5	0
Teachers	1	10	50,1	2
Nurses	4	65	42,0	13

2.5 Data collection

A survey can be a suitable instrument for several different aims and objectives. A survey is a written report where respondents are asked either open-ended or closed-ended questions (Haraldsen, 1999). Most commonly survey is designed to obtain information about the prevalence, distribution and interrelations of variables within a population (Polit & Beck, 2008). However, a survey can also be suitable for collecting qualitative data, with the use of open-ended questions. In this study data collection was done by a survey where demographic data in terms of age and gender was collected. The nurses were also asked whether or not they had further education in palliative care. There was only one open ended question asked. In White et al's (2001) study the question was: "What do you wish you had been taught in nursing school about caring for dying patients or terminally ill patients and families?" I think this question can be misunderstood, and this is a potential weakness in White et al's (ibid) study. There can be an implication here that you should list only the things you wished you had been taught but didn't, and you might lose important areas that the nurses actually had been taught about in nursing school. To avoid the possibility of misinterpretations, the question was rephrased to:

"What areas do you see as important for nursing students to learn about through the nursing education when it comes to palliative care?"

The respondents were asked to list 1-5 alternatives, like in White et al's (2001) study. So on they were asked to rank their answers in accordance to importance. The reason why this is done in two different turns is to avoid that the respondents neglect to list some areas they consider to be less important, if they think they have to list the most important first.

2.5.1 Ensuring a rigorous collection of data

Several considerations were made to ensure the questionnaire was rigorously developed which I will account for in the following. The instrument, a written survey questionnaire (see appendix IV), was developed with a view to give no room for misinterpretation. It should be self-explicative and give all the information necessary for the respondents without the need of my presence when filling out the questionnaire. This was important as some of the respondents were given the questionnaires in their mailbox, and had to fill it out on their own. The instrument was tested on six nurses with different backgrounds. They were asked to fill out the questionnaire and give comments on whether or not it was easy to understand the information given, if it was too much or too little information, if the design of the instrument was appropriate, and if there were any confusion on how to fill out the questionnaire and rank the answers. The instrument was adjusted in accordance to comments. Some sentences were rephrased and the layout was slightly changed. For instance, I discovered that it could be difficult to understand if the ranking should be done from one to five, or that each answer should be given a rank, so that three answers could be ranked as "1" and two answers as "4". I rephrased the explanation on how to do this to avoid misunderstandings. There was also a discussion on where to place the explanation of the ranking. I wanted it to be read after the different alternatives were listed, so this would not be an issue when the respondents found the different areas. However, if the explanation is placed last in the questionnaire, there is a chance it might not be read. I tried to solve this by placing the explanation last in the questionnaire, but in a bold font, to highlight this point.

In White et als' (2001) study, the respondents were asked to rank all the twelve set areas from 1-12 according to importance. In my study, the respondents were also asked to rank their answers according to importance, but the rankings would be from 1-5 at the most. I believe this makes my instrument more rigorous in two ways. In White et als' study, the areas were already made out and the respondents ranked areas that might not have been what they had listed themselves if given the choice. Consequently the respondents in my study ranked the areas they actually believe is the most important, without the possibility of misunderstanding what the area is about or leaving out any area they might feel was also important. In addition to this I question the validity of the rankings when the respondents have to rank from 1-12 instead of 1-5. According to Polit and Beck (2008) numerous response options does not give a more precise answer, but will on the other hand make it more difficult for the respondent to see the difference between the different options. By asking the respondents to rank the five answers instead of twelve areas, I believe I enhance rigour of the rankings compared to White et al's (2001) rankings.

Having described the planning and carrying out of the study in the previous sections I now turn to a discussion on potential limitations of the study. This is succeeded by an account of the different ethical considerations made regarding this study.

2.6 Limitations

Some difficulties arose when collecting data in terms of response rates. It was difficult to approach all the students at the same time, as there was no compulsory tutoring in the different schools at the time of data collection. Originally I wanted to use students from three different schools, but in one of the schools I wasn't able to reach the students as a group at all. I decided to go through with the data collection in two schools and consider by the richness of the data whether it was necessary to continue collecting data. Two schools gave very information rich data, so the limitations in response rates turned out to not be a problem.

This study includes three different respondent groups, and there are differences in the number of respondents in each group. The students and the nurses constitute a much larger group than the teachers, which can cause difficulties when comparing groups. However, the respondents are purposefully chosen on the basis that they are information rich. According to Rice & Ezzy (1999) sample size is large enough when the researcher is satisfied that the data are rich enough. If the respondents are information rich, the number of respondents is not important. On a basis of this I would claim that even though the teachers are outnumbered in terms of quantity, they are very information rich, and their answers must be given as much weight as the other respondents. I want to take the respondents seriously, and what they say is not less important just because their groups of respondents are small. However, there might be a limitation in the quantification of data. Because the answers are put in tables to show how many said what, it might give an unjust overview of the finding when comparing numbers. As stated earlier, the tables are only meant for giving an overview of the findings, and not for making statements about generalization. Because of the fact that the tables are intended as additional information to give a better overview of the findings, the problem of this limitation is small.

Another limitation of the study might be that I can only describe a limited amount of studies and evaluations on different educational programs. It was very difficult to find literature that described the educational programs in detail, which could have made it easier to compare the findings in my study to the areas dealt with in the different educational programs.

In addition to this, the comparison to White et al's (2001) study is somewhat limited due to the choice of respondents. White et al's study had only nurses as respondents, and this makes the comparison of findings between the two studies limited. Even though this is a limitation when it comes to comparison, it also points to the strength of my study compared to White et al (ibid) as I have the opportunity to collect wider data.

2.7 Ethical considerations

When describing potential ethical dilemmas in the study, I will use Kvale's (2007) guidelines for making ethical considerations. Kvale states that in all parts of the study, there should be considerations in terms of three different aspects:

- Informed consent
- Confidentiality
- Consequences for the respondents

An informed consent implies that the respondents are informed of the aims and objectives of the study, the research plan and how the study is carried out, and possible advantages and disadvantages of participating in the study. Additionally the respondents are informed that participation is voluntary, and that they can withdraw from the study at any time. In my study, all this information is given in the information letter included in the survey (see appendix IV). It is specified in the information letter that the return of the survey is regarded as informed consent.

Confidentiality deals with ensuring not to publicize any information that can identify the respondents in any way. As a starting point, my study is anonymous. However, demographic data on age and gender were collected, and this is potentially indirect identifiable information. For instance there is a chance that there are only one or two men in a ward, combined with age, it is in theory possible to identify the respondent from the survey. Demographic data collected in the survey is only used to give a demographic profile of the different respondent groups as such, and it is not possible to identify in particular any of the respondents. Anonymity is consequently ensured. The information letter also includes assurance that confidentiality is ensured. In the thesis, no participating institutions are named.

Consequences for the respondents' deals with how the researcher should consider the potential advantages and disadvantages the respondents might experience from participating in the study. The researcher has to assess the consequences, not just for the individual, but also for the group the respondent represent. In regards to this

study, the topic of palliative care might be perceived as somewhat sensitive, and a potential cause of distress for respondents. It might be difficult to deal with issues on palliative care, if they recently have lost someone close. In an interview situation this would be an important factor to consider, and make sure the respondents didn't feel uncomfortable during the interview or in retrospective. However, this is a written survey with a simple question, and the possibility of the respondents feeling uncomfortable by filling out this survey is considered minimal.

This study does not involve research on vulnerable individuals, and it was not necessary to apply for approval by Regional Etisk Komité (REK) to go through with the study. Based on the fact that this from starting point is an anonymous survey, it is not notifiable to Personvernombudet for forskning ved Norsk Samfunnsvitenskapelig Datatjeneste (NSD. After discussing the issue of indirect identifiable information with NSD, the advice was to report the study to be on the safe side. The report back was that the study was not notifiable, see appendix I.

After this account of the carrying out of the study, I will now give an overview of the analytical process, describing how the different areas and subcategories were identified after thorough examination of the collected data.

3. Analytical process

The analytical process from which the identification of the seven areas and the 25 subcategories emerged, involved scrutiny and in-depth examination of the data. The data analysis process is a major part of any qualitative study, and this study is no exception from this rule. According to Patton (2002), the purpose of data analysis is to transform data into findings, but the problem of qualitative analysis lies in making sense of massive amounts of data. The researcher has to reduce the volume of raw information, find the information significant and relevant for the study, identify patterns and construct a framework for presenting the data and what they reveal. During this process there are no formulas for determining significance or perfectly replicating the researchers analytical thought process. In terms of validity and reliability, there is no short forward way to test this (ibid). Patton claims that in short, no rules exist except this: ”Do your very best with your full intellect to fairly represent the data and communicate what the data reveal given the purpose of the study.” I wanted to do exactly this, but also move beyond Patton’s point of good intentions and fair representation of findings.

Morse (2008) argue that because qualitative researchers don’t show the work behind the findings, the analytic struggles to make sense of the data and how they find the themes and patterns, the research can be viewed as simple and just a matter of ”talking to the folks” and summarize what they say. In this chapter I will show that my findings actually do represent the data, which is in line with Patton’s aim, by making use of the suggestion from Morse (2008); to show ”the plain hard thinking behind the end product”. I will describe the analysis process in detail and address the issues I struggled with in the analysis process. I will also include appendices to illustrate this process and give a view of the raw data. From this I can justify the decisions I made. This way, the reader is able to follow my analytical thinking, and also judge how interpretative rigour is ensured in the analysis process. Another way I have ensured theoretical rigour is by following principles described by different authors on data analysis on things to consider when analyzing.

To be able to do a thorough analysis of the data it was necessary to lean on different types of analysis theory in order to find an approach that fit the aims of this study. As a starting point I have used elements from Crabtree and Millers (1999) strategy for analysis of qualitative data. Crabtree and Miller describe three main strategies for analysis, of which one is called editing analysis style and is relevant for this study. Briefly described, this means that the researcher acts as an ”editor”, by interpreting the text and find meaningful segments. Once identified, these segments are sorted and organized into categories or codes. Specifically this means that you can find categories based on a thorough investigation of the data collected. After having done this, you go through the data again, and code each of the answers into one of the categories. As the aim of this study specifically is to find the different categories, or areas, related to palliative care and organize all the different answers into these areas, I found Crabtree and Millers (ibid) strategy to be highly suitable for my analysis.

According to Crabtree and Miller (ibid) the interpretive process consist of five phases, which they call describing, organizing, connecting, corroborating/legitimating and representing the account. You go back and forth in the process and repeat the different phases several times, in many iterative cycles. In the following sections I will elaborate on these phases described by Crabtree and Miller (ibid) and use them as a frame for presenting how the analysis was carried out. I will also use additional theory where I found Crabtree and Miller (ibid) to be inadequate in terms of specifics, when I needed more details on how to move on further.

3.1 The phase of describing

The describing phase serves as a link to the data collection process. It is a reflective phase where the researcher steps back from the field and analysis and reviews what is going on and what should happen next. The researcher should be revisiting reflexivity and the paradigm questions – for example changes and influences in the collection process, challenges of earlier assumptions and fantasies, influences of culture and language, strengths and weaknesses in the process, operating paradigm, consistency

of collection method and proposed analytic approach. These elements are not all relevant for this study, but the main issue to ensure rigour in this study is to give comments on reflexivity, or reflexive rigour as described by Rice and Ezzy (1999). This issue of reflexivity is briefly accounted for in the chapter of design and method, section 2.2 page 31, but I will elaborate on the subject by the use of additional theory in the following.

3.1.1 Reflexivity

Reflexivity is an important term in qualitative research that reflects on the researchers self awareness, political/cultural consciousness and ownership of one's perspective (Patton, 2002). Reflexivity is described as having two aspects: acknowledgement of the researcher as part of the setting, context or social phenomenon under study, and self reflection about one's own biases, preferences, stakes in the research and theoretical inclinations (Polit & Beck, 2008).

In this study the method is a written survey, and this reduces the issue of the researcher as part of the setting. However, due to practicalities there have been some differences in data collection as to how the questionnaires have been handed out. In some of the locations it was impossible to meet all the respondents at the same time, as they had no joint meetings at the time of data collection. Consequently, some of the respondents I have never met, and they have had their questionnaires in their mailbox and filled them out by themselves. Some of the respondents have had the questionnaires handed out to them by me, and I have had an introduction where I briefly present my study and myself. This has been a challenge as there is a chance I might give information that create a bias among the respondents. I have tried my best when giving the introduction to be aware of this fact. I have tried not to say anything that doesn't already say in the information letter, using more or less the same words and formulations and not give any kind of examples on how to fill in the questionnaire.

When it comes to my own biases there are some things to consider. The field of palliative care is not a field that I have any kind of special competence in. My

background as a nurse is from a casualty department where most dying patients have acute conditions, and palliative care is for the most part not an issue. This gives me some advances and some disadvantages. I have a minimum of preconceptions and I think this will give me an open mind in the analysis process as there are no given answers and nothing in particular I am looking for. On the other hand, the lack of extensive experience with palliative care might also be a disadvantage as I am at risk to ”miss the obvious” in answers given to me by experienced respondents who might take for granted that underlying meaning is understood by the researcher. The way to go around this is extensive reading on the subject palliative care on my part, and thorough examination of each answer to try not to miss anything. Another element in my potential bias is that there might be a difference in the questions I have to my findings compared to what an experienced palliative nurse would have. Would a researcher with a different background be able to see things that I don’t see, and find patterns I don’t recognize? Or maybe is it the other way around? This is unknown, and maybe also difficult to predict whether it is an advantage or a disadvantage.

3.2 The phase of organizing

In this phase, you choose an appropriate organizing style. Three different organizing styles are identified by Crabtree and Miller (1999); template, editing and immersion/ crystallization. The three different styles are distinguished by the timing of classification and by the process of organizing. With the template style one is entering the text with a classification scheme. With the editing style one is entering the text and later developing the categories through direct interaction with and sifting and sorting of the text. The immersion/crystallization process moves directly from entering the text to making connections, without the development of categories or codes. The researchers intuition and reflexivity work are the primary source of interpretation.

In my study, the style chosen is editing analysis style. Categories are identified from the collected data from the survey. This is an inductive way of doing analysis. Patton

describes inductive analysis as discovering patterns, themes and categories in ones data. Findings emerge out of the data, through the researchers' interaction with the data (Patton, 2002). According to Crabtree and Miller (1999) the interpreter begins to segment the data by identifying what information is relevant to the research question, and then categorizing, cutting, pasting, splitting and splicing – and find the so called meaningful segments. Several considerations were made in order to do this and the decisions were made with a particular intention; to ensure that in-depth information from the data was not lost in any part of the process.

I started out by thinking that in this study each and every answer given in the survey was considered a meaningful segment. From these meaningful segments I would find the different categories, or areas. I read through all the data at first to get a sense of the whole, as recommended by Creswell (2003). I had 140 respondents who together had given 670 different answers, and this was the number of answers to categorize. When I started working on the analysis, I soon realized that it was impossible to go through with this approach. A lot of answers had several different meanings and areas listed in one, and it would be impossible to view them as one answer connected to one category or area. To illustrate, one answer was the following:

"*Knowledge on how to relieve symptoms in regards to pain, dyspnoea, fatigue, xerostomia, obstipation, anxiety, depression, interaction between physical and existential symptoms, help to coping with cancer diseases. At the same time holistic thinking (hospice philosophy).*"

It is difficult to put one label on answers like this and say what it is actually about, so I decided that the best approach was to go through all the answers and split them into new, meaningful segments. The above example was split into four segments:

- Knowledge on how to relieve symptoms in regards to pain
- Knowledge on how to relieve symptoms in regards to dyspnoea, fatigue, xerostomia, obstipation

- Knowledge on how to relieve symptoms in anxiety, depression, interaction between physical and existential symptoms, help to coping with cancer diseases

- At the same time holistic thinking (hospice philosophy)

This way each answer only had one meaning and I was able to connect each meaningful segment into a specific area. I did not risk losing any of the information in the data, as could be the case if I labeled answers to areas that only applied to parts of the answer. The result was that 140 respondents did not give 670 different answers, but 700 different answers. I decided to relate to the 700 answers instead of the original answers. I believe I can justify this decision by the same intention as mentioned above, to ensure that in-depth information from the data was not lost. The respondents were asked to state up to five answers, and there are differences in how many answers has been given. The number of answers given is not really an issue, as the purpose is to find out what are the actual areas the respondents view as important. This way some respondents gave only one answer, whereas other respondents could give eight or nine answers, depending on how many answers were split up. In the previously mentioned example that was split into four, the respondent had listed four other answers as well. Consequently, this respondent gave eight different answers.

To be able to trace the answers back to the originals, I made a data matrix where I put the original answers, with ID and rankings, with the split answers and an open row for the area I was going to link each of the split answers to. The three groups of respondents were handled separately, in three different data matrices. For example of this, see appendix V. I believe that the decision to do the analysis this way can be justified by the purpose of using the particular method chosen in the first place. The initial purpose of asking an open-ended question with a ranking in the survey was two-pieced: I wanted in-depth information and as many aspects and thoughts from the respondents on what was actually important as possible.

After organizing the split answers in this data matrix with the rankings linked to them, I started the work on finding the different categories. I decided to use the term

”area” instead of ”category”, as this is the term used in the survey. When I read through the data, I made some notes while reading about what was standing out, and what I thought could be possible areas. I tried to go through each and every answer, code the answers, and put them into areas one by one. For each answer I asked my self: ”what does it say?” and then ”what is this about?” The first question would give me a code, a descriptive view on the answer. The other question would lift the answer and give me the area that might apply to several other answers. This was not a very successful approach. Even though I had read through all the data, it was difficult to find the different areas when I saw the answers one by one. Crabtree and Millers (1999) different approaches didn’t give me the tools I was looking for when trying to find the right areas. The use of a data matrix helped me organize the answers, but the areas didn’t stand out in any way. I tried visualizing by combining the answers that contained the same words from the data matrix, so called in vivo coding, and see which areas were the most predominant. But even though the answers contained the same words, as for example ”pain”, I found that the meaning of the answers could be very different.

To follow the same example, some answers dealt with how to relieve pain, some with how to pick up on whether or not the patient were in pain, some dealt with pain medication, some with alternative pain methods. It was difficult to spot the patterns and find the areas in the data matrix. I decided to try Krueger and Casey’s’ (2000) ”long table approach”. This is a very simple yet effective way of organizing the data so its easier to find connections between the answers and discover and develop the different areas (ibid). The long-table approach consists for the most part on concrete tips on how to organize the data. From a starting point, it is how to use printed transcripts, scissors and colors to get an overview of all the data. According to Krueger and Casey (ibid), you should print two copies of the transcript, number each line of the transcript to be able to trace it back and cut one of the transcripts apart to have individual quotes. These tips transferred to my study meant number each of the answers, and cut them out individually. In answers with multiple meanings, I cut out the different meanings so one answer could be cut in two or more parts. In order to

enhance interpretative rigour, I cut out the answers without checking the data matrix. I checked if I had split the answers up the same way in the two operations. There were a few inconsistencies, and I did a new consideration on how to split up those answers. I now started to make clusters of different answer with similar content. The tip from Krueger and Casey (2000) when doing this was to ask yourself: ”Is this like something that has been said before?” I put the answers one by one on the floor, on different pieces of paper, one for each cluster. I made notes on the papers while clustering, on what this cluster was about, and why I put the different answers exactly there. I didn’t lose any of the meaning or depth of information, as the answers were still in its original form. I had up to 20 different clusters, or areas, with some variance in number of areas among the different respondent groups. After all these decisions were made, I had a starting point for my categorization. These different areas were quite specific and descriptive, I did not try to make interpretations or find the underlying meaning in this phase.

3.3 The phase of connecting

This phase refers to the discovery of themes and patterns, making linkages between categories, developing models and generating new theory. Techniques for doing this is for example creating maps and diagrams and from this suggest new connections and patterns, visualization of concepts and categories, use of data matrices, writing short stories or developing vignettes from the data (Crabtree & Miller, 1999).

In this phase I went deeper into the data material and connected several of the different areas. The original areas could in some cases represent subcategories. I changed some of the answers that appeared to fit somewhere else than where I originally intended. I tried out different alternatives as to which area to apply different answers. As a working example, I will illustrate this process in the following. Many of the respondents listed ”relatives” as an important area. This was a subject that stood out in my first read-through, and it seemed obvious to have this as a separate area. There were quite a bit of differences in the descriptions of what was important

about the relatives. For instance, the students had to include the relatives when dealing with the patient, know how to communicate with the relatives, they should have insight in the psychological issues the relatives had to deal with in a difficult situation, they needed to follow up on the relatives after the patient died, the relatives could give valuable information about the patient and make it easier to give the best possible care to the patient. My first suggestion was to formulate the area: ”How to relate to the relatives.” Two aspects in how to relate to the relatives stood out, so I decided to have 2 subcategories: 1) ”The relative as a collaborator and a resource for the patient” and 2) ”The nursing student as a resource and caregiver for the relative”. Another area I worked on at this time was about the interaction between the student and the patients, this was also an area that was mentioned a lot. I tried different formulations to catch what it was really about, it dealt for the most part with different aspects of communication and how the students own values and attitudes would have an impact on the interaction with the patient. I discovered that I had to split up a lot of these answers because in a lot of cases the patients and their relatives were both referred to in the same answer. For instance, ”how to communicate with patients and their relatives”, or ”be supportive towards both the patient and their relatives in a difficult situation”. I got the notion that in many cases, the patients and the relatives were seen as a unit, and that the main issues were the same in both groups. The answers circled around how the students should relate to both relatives and patients and the interaction and cooperation in between the three groups. I decided to make a linkage between the two areas and like many of the respondents, view the patients and their relatives as a unit. The new area was now formulated ”Interpersonal skills in regards to patients and their relatives”. Subcategories were ”Interaction and communication with patents and their relatives” and ”Personal qualities and experiences”. This is an example of how the areas could change as I re-read and went deeper into the data material. What at first stood out as an obvious area wasn’t necessarily what I ended up with. Another example of this is the area of mental health issues. Originally the answers describing mental health issues were linked to the area of symptom management. The thinking behind this was that the body and mind go together, and psychological reactions like anxiety and grief are normal reactions to a

life threatening disease and can be viewed upon and attended to in the same way as physiological symptoms. However, there were different aspects of this matter that could not be related to symptom management, like existential questions and the attending of quality of life. I decided to view the area of mental health as a separate area, because this in a better way would reflect the content of the answers given by the respondent.

Like in White et al's (2001) study I wanted to present the findings in tables. Before I could make the tables I had to make some decisions on how to handle the data. As explained earlier, all answers were ranked from 1-5 according to importance, where "1" was viewed as the most important. I kept the ranking in each answer the same in both split answers. To illustrate one answer is this, originally ranked as "3":

"Good knowledge on how to relieve symptoms. Basic values and knowledge about the spiritual dimension."

I split this one answer into two separate answers, both ranked as "3":

- Good knowledge on how to relieve symptoms.
- Basic values and knowledge about the spiritual dimension.

The consequence of doing it this way is that all together I had more different answers, each with a ranking, even though the original answer had only one ranking connected to it.

Even though I end up with more rankings than what was originally given me by the respondents, the fact still is that both statement nr. 1 (Good knowledge on how to relieve symptoms.) and statement nr. 2 (Basic values and knowledge about the spiritual dimension) are originally ranked as "3".

Another issue was that some of the respondents did not rank their answers. Some might have forgotten, but others made comments on the survey sheet that it was difficult to rank the answers, as they were all equally important. I decided to include all the data in the analysis process were I found and described the different areas to

not lose any information. All data is consequently a part of the analysis of the findings and conclusions. However, there was a problem when I wanted to make tables showing how many of the respondents had listed the different areas, and how they were ranked. The tables' main purpose is not to be able to generalize, but to give an overview on how many of the respondents who listed the different areas and how they ranked them. From 140 respondents just a few were not ranked, so I decided not to include the non-ranked answers in the tables and the calculations in them. Not so much information was lost, and the tables themselves don't say anything about what the areas are actually about. In the description of the areas, the non-ranked answers are included.

3.4 The phase of corroborating/legitimating

This phase consist of re-viewing the text seeking to confirm the internal consistency of interpretation. The interpretations need to be consistent with the view of the respondents. The researcher should evaluate whether or not the interpretation answer the problem that motivated the study in the first place. Strategies for doing this can be for example searching for alternative explanations, disconfirming evidence, negative cases and member checking. One can test the interpretation by make several others view them, such as other members of the research team, other researchers, clinicians, or the people the study is concerning. In every step of the analysis process, I have discussed my decisions with a fellow student whom I have worked with, as well as a research team and my supervisor. I have also leaned on the following principles made out by Patton on things to consider when analyzing.

According to Patton (2002) the categories should be judged by internal and external homogeneity. This is described as the extent to which the data belong together (internal), and the extent to which differences among categories are clear, with no overlapping (external) (ibid). When I tried out different answers in different areas and discussed the decisions I made on where to put them with a co-student, I ensured internal homogeneity. An example of ensuring external homogeneity was the

decision to put the answers that dealt with both the patient and the relative into the area of interpersonal skills as opposed to two different areas where one dealt with the patient, and one with the relatives. I found that there was an overlap in the two original areas as they dealt with the same thing, and decided to combine the two areas into one.

The category set now had to be tested for completeness: viewed internally the categories should appear to be consistent, viewed externally the categories should give a whole picture of the data. Also the researcher have to check that the category set include data given, or if there are un-assignable cases. The category set should be reproducible to others, and it should be credible to the respondents (Patton, 2002). Whether or not the category set is credible to the respondents has not been tested, as this is not expedient in this study. One respondent will not have answered in a way that applies to all areas. The different areas are a product of the combination of all the different answers, and it would make no sense to go back to some of the respondents and ask if the areas can apply to what they answered. I have however, checked that the category set include all relevant data and to some extent if it is reproducible to others by discussing the decisions with my co-student. These are all actions that will ensure interpretative rigour and inter-rater reliability in the study.

As a summary of this analysis process, I will use the first working example and give an overview of how the answer was processed and categorized in the following table.

Table 7

Example of processing data

Original answer	Original ranking	Split answer	New ranking	Area
Knowledge on how to relieve symptoms in regards to pain, dyspnoea, fatigue, xerostomia, obstipation, anxiety, depression, interaction between physical and existential symptoms, help to coping with cancer diseases. At the same time holistic thinking (hospice philosophy	1	Knowledge on how to relieve symptoms in regards to pain	1	Pain Management
		Knowledge on how to relieve symptoms in regards to dyspnoea, fatigue, xerostomia, obstipation	1	Symptom management
		Knowledge on how to relieve symptoms in regards to anxiety, depression, interaction between physical and existential symptoms, help to coping with cancer diseases.	1	Mental health issues
		At the same time holistic thinking (hospice philosophy)	1	Knowledge of palliative care

3.5 Representing the account

This phase deals with the sharing of new understandings and interpretations and what has been learned in the researching. Crabtree and Miller (1999) suggest that this could take the traditional forms of a research article for a journal, a monograph or a book, but also in other ways, like a performance, writing a story or a poem, presenting at town meetings etc.

My findings will take the form of a monograph that will be presented to each of the sites where I had respondents. I will also make an effort to write an article ready for admission in a peer-reviewed journal after finishing the thesis. Possible angles in the article would be presentation of the findings in a Norwegian article that deals with

palliative care or nursing education, or on the methodological considerations and issues throughout the study.

3.6 Comparison with White et al in regards to analysis

I have modeled on White et al's (2001) study, which was the inspiration for choice of design in the first place. There are however, differences in the two studies and this has implication for the analysis process. In White et al's (ibid) study, the survey was carried out in two phases. First they asked 56 nurses to answer the question: "What do you wish you had been taught in nursing school about caring for dying patients and their families?" From this they had 160 different answers, and this was the basis for developing twelve different categories, or core competencies, which is the term they use. For the second phase they had 750 respondents who were asked to rank the twelve different categories from 1-12 in regards to importance. In my study, these two phases are done in one segment. There are both advantages and disadvantages in the two approaches. I have explored the weak links of the White et al's (ibid) study, to be able to modify and improve them in mine. Some of the issues I comment on in White et al's study might have causal connections to the different forms of presenting the study. My study is presented in the form of a monograph, and White et al in the form of an article, with limited possibilities to elaboration. It is however, important to point a finger at the limitations in White et al's (ibid) study when I aim to in some ways compare the two studies, both methodologically and in regard to findings. The crucial part of the analysis process in my study, is finding the different areas that the respondents claim to be important. This process of developing the twelve categories from White et al's (ibid) first survey is barely mentioned in the article. One sentence sums up the entire analysis process: "The responses were collated, like items were combined, themes were identified and the literature was searched for constructing twelve areas representing issues in EOL care." It is difficult from this article to do any judgements on to which extent the defined categories reflect the data in a valid way. By giving detailed descriptions of the analysis process, I'm able to give a

picture of the analytical thinking that sits behind the developing of the areas in my study.

When reading the article, I also found it difficult to understand the meaning and content of the twelve different categories. Each category is only described in one sentence, and the article does not elaborate on what the nurses actually said about the different categories. I addressed this issue in two different ways. First of all, by thoroughly describe each of the categories when presenting the findings and secondly, to clarify the content of the categories by making subcategories and include them in the presented tables (see appendices VI-VIII). This way it is possible to explore the underlying meaning of the defined categories, both from the tables, and also from the thesis. The categories defined by White et al (2001) are quite concrete and descriptive. My aim was to lift the categories to a higher level by exploring the content of the categories and what they were really about, to drive the data further. By the words of Morse (2008): ”Those who are outstanding researchers push their analysis beyond the obvious, so that their studies surprise and delight”. This might be a bit too ambitious of a goal for a master student, but what I at least tried to do was to move beyond this and avoid descriptive formulations of the areas and rather show the underlying meaning within. In addition to this I described in detail what the respondents actually said about the different areas in the presentation of my findings. Put together I’m able to give an overall picture of the findings, both in detail, but also on a higher level. This as opposed to White et al’s (2001) study, which described each area in one sentence.

After having given a detailed description of the analytical process in this chapter, the next chapter will include a presentation of the findings emerging from this process.

4. Findings

4.1 The presentation of findings

The presentation of the findings will include the seven main areas with the 25 subcategories, and elaboration on what was said about the different areas. Hence, this presentation will give the answer to the first research question raised:

”What do nurses, nursing students and nursing teachers say about the important areas for nursing students to learn about in palliative care?”

Some comments on how the findings are presented and the thinking behind is in order.

Originally I intended to present the findings of the different respondent groups separately. In the data analysis process, I did inductive analysis in each of the three respondent groups. It seemed suitable to present the findings from the three groups separately as extensive work was done on what the different respondent groups answered in relation to each other, and tables were drawn with the different groups as starting points. One of the research questions were phrased as: ”What are the differences and/or similarities between what the different groups of respondents say about the important areas for nursing students to learn about in palliative care?” However, the main problem of the study is the following:

”What are the important areas in palliative care for nursing students to learn about through the nursing education?”

If the findings from each group were presented separately, it would be more of an emphasis on the interrelationship between the groups than the main problem itself. I decided to present the findings across the groups as one, and consider the differences and similarities in between the groups in the discussion section 5.2 page 96.

At the beginning of the analysis process, the different groups came out with quite different areas, but during the analysis process, a pattern emerged: the main areas were somewhat the same, but there were differences in how the students, the teachers and the nurses described each area, and what they emphasized in the different areas. For this reason I decided to have subcategories in each of the areas. This gave me the opportunity to give a more detailed description on both the differences and similarities in the respondent groups. I found White et al's (2001) presentation of their findings limited, as there was no elaboration of what the different categories contained, and no subcategories.

I was influenced by Bayat's (2007) study on how they presented their findings. Even though the theme of this study is very different from mine, it's possible to draw links and model on how they present their findings. In the Bayat study, they had the same experience as in mine; most of the broad categories in different groups were similar, but subcategories were different. What they did specifically, was to analyze separately three different folders of answers, and came out with three or four large categories in each folder. It turned out that two of the folders had identical categories, whereas the third folder had different categories. In comparison, I have some areas where the subcategories are different within the groups, and some areas where the subcategories are the same. They decided to present the findings in a table with a general overview on all the categories found combined with the subcategories, without any form of quantification linked to it. In addition they had tables from categories were quantifications were made.

Inspired by the clear overview of the results Bayat (ibid) gave, I did the same. This way I was able to give a very good overview of the total findings in my study. This table (8) is presented at the end of this section, page 63. In addition I made a table in each of the three different groups where I presented the findings in a somewhat similar way that White et al (2001) did. White et al's table included four columns. They listed the different areas (twelve in total), how many ranked the different areas as "1", mean and standard deviation. My tables included three additional columns. One that listed the subcategories, how many answers who applied to the different

subcategories, and how many answers who applied to the different main areas in total. These three additional columns are not necessary in White et al's (2001) study, as there are no subcategories, and the number of answers in each category is the same as the number of respondents. I believe that this additional information in my tables will give a broad overview of the entire data set in a more extensive way than in White et al's (ibid) study, and is so forth another argument of why an adjustment of White et al's study was in order.

When presenting the findings I have to take into consideration the fact that I have a substantially large amount of data. I have 140 respondents and 700 different answers. To report everything in detail would take too much of the thesis, in total there is seven main areas and 25 subcategories. I had to make a decision on whether to present each areas as a whole, or if all the subcategories needed to be described. The main areas are so broad and contain a lot of information, and quite a few of the subcategories within an area are very different from one another. Thus, I decided to describe all the subcategories, but with as few words as possible without loosing any depth of the information. I will use quotes in each of the subcategories directly from the respondents, these are italicized and put in quotation marks. The reason for using the quotes is to exemplify and bring to life the voices of the respondents in this study. Everything in this chapter will be a reflection of what is directly stated by the respondents. This way I stay true to the data and ensure interpretative rigour. The different areas with the following subcategories emerging from the respondents are as follows:

Table 8

Overview of findings

Areas	Subcategories
Interpersonal skills in relation to patients and their relatives	Encounters with patients and their relatives – communication and interaction
	Personals qualities and experience
Symptom Management	Knowledge
	Practical skills
	Observational skills
Pain Management	Theory on physiology and pain therapy in general
	Medicamental therapy
	Non-medicamental therapy
	Observational skills
	Ethics
Knowledge on palliative care	What is palliative care?
	Original diagnosis
	Hospice philosophy
	Alternative medicine
Contextual conditions	Interdisciplinary cooperation
	Legal issues
	Organizing the environment
	Timely issues
	Differences in cultural background
Mental health issues	The spiritual dimension
	Handling grief
	Quality of life
	Other emotional aspects of palliative care
The concept of death	Knowledge on the process of dying
	Practicalities concerning the deceased patient

I will elaborate on the different areas in the following.

4.2 Interpersonal skills in relation to patients and their relatives

This area deals with different aspects that have an impact on the relationship between the student and the patient with their relatives. This is an area that has been highly emphasized by all the different respondent groups. Two subcategories stood out when dealing with this subject: the encounter between the students and patients/relatives, and the qualities in the students themselves in regards to their own values and attitudes. Subcategories were consequently defined as:

- Encounters with patients and their relatives – communication and interaction
- Personal qualities and experiences

The two subcategories will be presented separately.

4.2.1 Encounters with patients and their relatives – communication and interaction

The respondents frequently mentioned how to communicate and interact with the patients and their relatives as an issue. Different aspects of this encounter were discussed. Some would say only ”communication” or ”interaction” as an area, but others elaborated on what communication and interaction actually dealt with.

”How to communicate with the patient who is dying and the relatives. It’s difficult to know what to say and do in that situation.”

Some of the respondents stated that communication skills were important both in relationship with the patient and their relatives, others said only patients, others again said only relatives. I will use the term ”patient/relatives” when discussing the issue, since communication was the main theme were respondents saw the patient and the relative as a unit.

The main emphasis of communication was the general skill of talking to the patient/relatives. Mostly on how to talk about death and dying but also how to talk about hope, feelings, the patients disease and how to organize their last time in life. Not just difficult subjects were mentioned when it comes to how to talk to the patient/relatives. How to talk about everyday life were also emphasized. How to make sure that conversations not only were concerning difficult issues and tragedy, but also on positive things in life - how to make small talk and light conversation with dying patients and their relatives. As a summary, I would say that the respondents stated that both ”the ordinary conversation” and the ”extraordinary conversation” were of great importance. In the encounter with the patient, the awareness that both verbal and non-verbal communication were equally important was underlined as an issue.

In terms of interaction, the importance of listening to the patient/relatives and open up to questions they may have were made a point out of.

” Purposeful communication and active listening. Open up to questions”.

The students need to respect the patients right to self-determination and cooperate with the patient to make sure self-determination is implemented in the palliative care process. How to carry out palliative care on the patients term are essential, and the students need to find out what issues are important to the patient and how to meet their wishes for how the situation should be organized. The respondents argue that in many cases, little things mean a lot; this is referred to as ”significant trifles”. The students also have to see the overall picture of the situation the patient is in, and not just the disease or what goes on in the patients’ room.

Some of the answers dealt only with the relatives as a specific group as opposed to the patient. The emphasis in these answers was mainly on two different themes:

- How to be supportive towards the relatives in a difficult situation and acknowledgement of the fact that the relatives could be a vital collaborator for the student when dealing with the patient.

”Communicating with the relatives when they are tired and in grief”.

In other words, how the student can be a resource for the relative, and how the relative can be a resource for the patient.

- How to include the relatives as a part of the patient in his/her situation were also stressed as a main point. The student need knowledge on the possibilities for organizing the situation in a way that gives the relatives the opportunity to be a part of the patients life the last time. The relatives should be informed about progress and practicalities, and to some extent be included in the decision making about the patient.

How to relate to children as relatives were mentioned as a particular subject the students need awareness on.

4.2.2 Personal qualities and experiences

This subcategory deals with the qualities within the students in regards to values, attitudes and their own experiences and how this impact on the relationship with the patients and their relatives.

”To have empathy without being overwhelmed by sympathy”.

Different aspects were listed, both on how the students need to take care of themselves and their own reactions, and also how they should take care of the patient/relatives and their reactions. It was argued that the students’ previous experience with death and dying in their own life had an impact on how the were able to relate to the issue now. The importance of preparing the students for the fact that palliative care can be very difficult and demanding on them and lead to strong reactions on their part was stressed by quite a few of the respondents.

”How to feel secure with oneself when daring to be exposed to a difficult situation, and be a support for both the patient and the relatives.”

The respondents expressed that there are challenges in two directions. The students meet dying patients and relatives, whom they might grow a relationship with, and the students might experience emotional distress when they have to watch the patients die. The students also have to face their own mortality in a way they might be unprepared for, and the students will often experience a high level of death anxiety. In some situations they might meet patients in a somewhat similar stage of life as themselves, who are dying.

”Prepare the students to meeting their own mortality. Meet people in similar life situations as their own, who are dying.”

This is a particular difficult situation to encounter, and the students will be confronted with their own death in a way that might be unfamiliar to them. Death should be a natural subject to talk about, and regarded as a part of life.

”The students relationship to their own death.”

The students that are unfamiliar with dealing with death can have strong emotional reactions to the situation they find themselves in. These reactions or feelings need to be normalized, as a part of the challenge of being a nurse, and the ability to cope with these feelings are essential for a nursing student. All together, the respondents frequently mention the issue of taking care of oneself when dealing with patients facing death.

The respondents use several differing terms to describe the different qualities that are essential for the students to have in order to carry out palliative care. Most commonly is the term ”empathetic” used for what qualities are the most important when encountering patients and their relatives. Among other terms that are mentioned to describe the palliative care nurse is comforting, caring, listening, thoughtful, friendly, loving, respectful, understanding and humble. These are all descriptions of attitudes towards the patient and relatives and in what manner the students should act.

Another major theme within this subcategory is ethics. The students need to know the ethical guidelines in palliative care, and how to reflect on ethical problems and dilemmas.

”Ethical questions revolving around how to behave when relating to dying patients and their relatives.”

Some of the respondents claimed that it’s not always only one solution that is right, and the optimal solution for the patient might be impossible to carry out due to practicalities. Examples of ethical dilemma noted by the respondents, is when there are disagreements between what the relatives and the medical personnel believes is the best care for the patient, mostly on whether or not to prolong treatment. The debate of euthanasia is also mentioned as an area of reflection. In relation to ethics, taking care of the patients’ dignity was regarded as important.

4.3 Symptom management

The area of symptom management revolves around how the students have to be able to pick up on the patients’ cues in regards to symptoms and act on the basis of this. This area deals with all physical symptoms the patients might experience, and how to handle the different symptoms. The symptom of pain is taken out of this area, as the respondents had an overwhelming emphasis on the issue of pain. The respondents describe the symptoms in various ways, and there are differences in what they actually say about what is important when handling symptoms. The subcategories in this area are consequently chosen on the basis of emphasis in the answers in regards to symptoms. The symptoms that apply to all different areas will be describes in subcategory number one, knowledge. There are three subcategories in this area:

- Knowledge
- Practical skills
- Observational skills

4.3.1 Knowledge

The respondents stated that emphases in palliative care sometimes very much revolved around the symptom of pain, and that there might be a general understanding, or misunderstanding, that this is what palliative care is all about. According to the respondents, this is a severe simplification of what palliative care is about, and there are several other issues that need to be addressed in the form of other symptoms. The students need comprehensive knowledge on what symptoms the palliative patients are likely to experience.

”The students need knowledge about important symptom relieving methods. Their focus should be on both medical and nurse related relieving methods.”

The students also need to know what treatments are available for different symptoms, especially in regards to medication, like for instance sedatives. How to prevent complications in regards to long-lasting stays in bed is also a subject where the students need knowledge. Additionally they need knowledge about how to handle cannulas, CVC’s, VAP’s and so forth. Another issue described by the respondents was dealing with the patients in a holistic manner. The students need to know that by addressing some of the symptoms, others may be prevented. To be able to act when the patients are troubled by various symptoms, the students have to have an understanding of what symptoms may occur. Theoretical introduction can give knowledge about his. A number of different symptoms were stated as important to have knowledge about by the respondents. One of the most frequent symptoms mentioned was nausea. Knowledge about how to prevent nausea and also how to treat it was viewed as important. In connection with this, knowledge about nutrition were also a factor, how to take nutrition into consideration when dealing with nausea. Nutrition was also mentioned in connection with obstipation and diarrhoea, which were yet other symptoms frequently reported by the respondents. Other symptoms stated as important are dyspnoea, xerostomia, skin wounds, radiation damages and decubitus.

4.3.2 Practical skills

In addition to having knowledge about the different symptoms, the students also need to know how to practically carry out relieving measures. How to address the different symptoms mentioned earlier with suitable actions so the patient experience the best possible care. When it comes to practical skills, many of the respondents stated that comfort care is the most vital skill as it deals with the overall well being of the patient. Other skills mentioned are the ones that address the different symptoms in particular, like how to give infusions and injections, treatment of wounds, mouth hygiene, how to give purgatives and how to use decubitus preventing equipment.

4.3.3 Observational skills

The students have to be able to observe the patient and identify symptoms that need addressing, as the patient might not be capable of communicating this himself. The different observations mentioned by the respondents are respiration, dehydration, xerostomia, gargling, smells, sounds, colors and marbling. The student need to learn how to notice changes in the patient and from the observations understand what the needs of the patient are.

”The students have to be able to observe and identify the patients need, and learn how to meet these needs on the basis of their observations”.

There was an emphasis on clinical assessment skills and how the students should assess the patients’ situation from the observations made by the students.

4.4 Pain management

Pain management concerns how the students address the issue of pain in the patient. This area corresponds with the area of symptom management and deals with how the students have to be able to pick up on the patients’ cues in regards to pain and act on a basis of this. Different aspects of pain management are mentioned, and subcategories are the following:

- Theory on physiology and pain therapy in general
- Medicamental pain therapy
- Non-medicamental pain therapy
- Observational skills
- Ethics

It has been underlined by the respondents that the concept of pain also includes other forms of pain than the physical one, and that psychological and spiritual issues also are relevant to pain and can actually be the cause of physical pain. However, these psychological issues are discussed in the area of mental health issues, and this chapter is limited to the issue of physical pain.

4.4.1 Theory on physiology and pain therapy in general

”Understanding of pain - different types of pain and different types of pain relieving”.

To understand the patients’ pain and address this issue, the students need to obtain general knowledge about the concept of pain. There are different aspects of pain that are essential to have knowledge about. One important area is the physiology behind the pain, to understand anatomy, physiology and the nervous system and what makes the body experience pain. The students also need understanding of the fact that there are different types of pain, for instance acute pain as opposed to chronic pain or cancer related pain, like metastasis into the skeleton.

”Understanding of pain - different types of pain and different types of pain relieving”.

They also need to understand what kind of pain therapy is necessary in different cases.

”Knowledge on pain therapy – what kind of therapy is available, and where to turn to if help is needed”.

How to interpret signs of pain in the patient when the patient no longer can verbally express pain is important. Also to understand that there are differences in the patients' pain threshold and that pain is an individual experience that requires individual treatment. The students need to understand the consequences of being exposed to pain on a long-term basis and how pain can have an effect on the entire body, even though only one part of the body is directly affected.

4.4.2 Medicamental pain therapy

Medicamental pain therapy is a profound part of the palliative care treatment, and it is essential that the students have a thorough training in how to handle medications. Basic pharmacology is a starting point and an area that need to be explored by the students. They have to know what kind of medication is necessary for what kind of pain, how the medication affect the body in terms of working mechanism and side effects.

"Knowledge on how different types of medication works, and possible side effects".

The students need knowledge of the different types of medication and the names and normal dosage of the most common drugs. Calculation is also a necessary skill when administering medication.

"How to administer pain medications and knowledge on the most common medications and dosages".

A number of different ways of administering medications are available, and the students need training in how to do this. Tablets, capsules, injections, infusions and analgesia pumps are mentioned as the most common ways of administering medication. The respondents underlined that medication in palliative care patients is different from most other patient groups, as the goal only is to relieve the patient from pain, without taking into consideration the possible addiction to strong drugs.

Another subject mentioned by the respondents is how to identify in the patient when the medication dosage needs adjustments as pain increases.

4.4.3 Non-medicamental pain therapy

An important issue in pain therapy is the use of non-medicamental measures, often referred to as complementary pain therapy.

”Non-medicamental pain relieving strategies – conversations, soothing environment, massages, skin care, treatment of wounds, meditation, water therapy, light treatment”.

The importance of this is highly emphasized by the respondents, and several different actions are described. I will mention all of them briefly: Massages, physical contact, anxiety restraining techniques, music, closeness to the patient, calming surroundings, changing of the patients position, safety, light treatment, water therapy, skin care, relaxation techniques, heat, and guided imaginary.

The main emphasis is concerning the students’ awareness of the fact that medication in itself is not enough, and that non-medicamental pain therapy is part of a holistic way of viewing the patient.

4.4.4 Observation

Observation skills are essential in all aspects of caring for palliative patients, but are mentioned the most frequently in regards to pain.

”How to be able to recognize when the patient is in pain”

How to observe symptoms of pain is of great importance, and the students have to interpret the patients’ cues and be able to act on it. This is especially important when the patient no longer can express their potential pain verbally.

”How to interpret signs of pain when the patient have lost their ability to communicate verbally”.

According to the respondents, symptoms of pain and symptoms of anxiety might be similar, and difficult to interpret. To make an effort in picking up on the patients’

cues is vital, as there are quite different measures for how the students should address pain as opposed to anxiety.

4.4.5 Ethics

Ethics about pain relieving therapy is an issue to the respondents. There is a dilemma between allowing the patient to be relieved of pain, and being totally sedated and not able to communicate in the last phase in life. This has to do with quality of life, even in the last stage of life. The patients' autonomy has to be respected in these cases.

"Sedation of dying patients. Considerations of ethics and the autonomy of the patient in these situations".

4.5 Knowledge of palliative care

This area is called "General knowledge on palliative care" and deals with the different aspects in palliative care. Subcategories are the following:

- What is palliative care?
- Diseases
- Alternative medicine
- Hospice philosophy

4.5.1 What is palliative care?

Several of the respondents stated that the students have to know the fundamental essence of the term "palliative care".

"Basic knowledge on what palliative care is about, different methods".

What is it, why is it needed, in what situations and to what kind of patients is it used? Other aspects of knowledge about palliative care revolved around aims and objectives

in palliative care as opposed to other aspects of nursing care, and when to end treatments.

”The difference between palliative and curative care”.

The nursing role and what expectations the students will meet are also an issue. In addition the students need to know what kinds of treatment that are available and what kind of facilities the patient might be offered in this situations. Examples of this are palliative units in a hospital, hospice etc.

4.5.2 Original diagnosis

The importance of knowledge about the pathology of the disease that causes the patient to be in need of palliative care is underlined by many of the respondents. What kind of diseases can cause the patient to be in need of palliative care? The characteristics of the different diseases might cause different symptoms that the students must be aware of.

”The significance of the disease – how the pathology of the disease can give different symptoms in different diseases”.

Cancer is stated as the main disease related to palliative care, and the students need particular knowledge about this disease. Dementia is also mentioned. The treatments of the different diseases are also important to know. Even though the patients are not in a curative phase, they still require treatments to ease their symptoms. Knowledge about anatomy and physiology is equally significant. All together, knowledge about pathology, anatomy and physiology will make the students able to perceive conditions that require special alertness, and act on a basis of this.

4.5.3 Hospice philosophy

Respondents claimed that the students should have knowledge about the term hospice philosophy and what it means to work with this philosophy as a foundation. The significance of a holistic approach when dealing with patients is vital.

”Knowledge on hospice philosophy and the importance of a holistic approach”

It is also mentioned by the respondents that the students need to know the essence of the term ”Total pain” as made out by Cicely Saunders.

4.5.4 Alternative medicine

Alternative medicine is also listed as a subcategory among the respondents.

”Alternative medicine is important and can help in situations where medications are inadequate. For instance acupuncture”.

The students need knowledge on the different kinds of alternative medicine that are available and in what way alternative medicine might be supplementary to academic medicine. Acupuncture and healing are mentioned as examples of alternative medicine.

4.6 Contextual conditions

Contextual conditions refer to the different factors outside of the patient/nurse relationship that have influence on the patients’ life. The subcategories in this area is the following:

- Interdisciplinary cooperation
- Legal issues
- Organizing the environment
- Timely issues
- Differences in cultural background

4.6.1 Interdisciplinary cooperation

The importance of interdisciplinary cooperation was highly emphasized by the respondents. There are several different occupational groups that can be good

collaborators in the overall caring for the patient and the students need to know who to turn to and how to relate to them. To understand the significance of the other occupational groups is a part of a holistic thinking.

”By recognizing the importance of interdisciplinary cooperation the students is able to address all need the patient has, not just the ones that nurses normally address.”

The students should be able to identify the different needs of the patient, and acknowledge when a different occupational group is more competent in addressing the patients’ need than themselves. Examples listed by the respondents are doctors, community care nurses, cancer nurses, public health nurses, anesthesia personnel, social workers, clergy men, nutritionists, cooks, musical therapists, teachers, physiotherapists and ergonomists. In addition to this, the students need to know about support groups for palliative care patients or support groups for specific diseases, like cancer. Another point made out by the respondent is the cooperation between the different sectors of the public health services. Cooperation between community health service and the hospitals is important and the students need to know the routines on how to go through the right official channels.

4.6.2 Legal issues

The students have to know the legal system to secure that the patients’ rights are enforced. The health service is controlled by rules and regulations and national guidelines, and knowledge about this is essential to be able to give the patients and their relatives the right information about the matter.

”Knowledge about how and where to obtain helping facilities and financial support for the patient to be able to optimize the care. Knowledge about rules and regulations concerning the patients’ right to decide where to end his life. (at home or in an institution)”.

The patients also need information on the different choices they have as patients in regards to where to stay and what kind of treatment is available. This also involves

knowledge about how to provide for financial support for remedies and other helping facilities.

4.6.3 Organizing the surroundings

According to the respondents, how the surroundings are organized are of vital impact on the patients comfort. The students can make an effort to arrange the surroundings in such a way that it gives the patient the best possible opportunity for well being.

”The environment and surroundings of the patient is vital and the students need to focus on this in order to take care of the patient as a whole.”

In the hospital or another kind of institution, the importance of a private room is essential, but also the opportunity to have people around and not be alone. If the patient is at home, there are different helping facilities that can be installed to make sure the patient is as comfortable as possible.

4.6.4 Timely issues

An issue that has an impact on the patients’ life, and the students’ opportunity to carry out the best possible care, is the matter of how to prioritize time. It is difficult to do a good job when pressed for time, and palliative care is a time consuming way of working, which need to be acknowledged.

”Time pressure is a great challenge and it’s difficult to feel that you do a good job when pressed for time”.

The students need to learn how to work under time pressure and at the same time have an emphasis and focus on prioritizing enough time for each patient to be able to do a good job.

4.6.5 Differences in cultural background

The encounters with patients from different cultural backgrounds are an issue when working with palliative care patients. The students have to know the different cultures and attend to their needs in accordance with their religion. For instance, it is stated by the respondents that different cultures handles pain differently, and use different pain therapies.

"Different cultures handle pain and pain therapy differently. It's important to know how to deal with this."

There will also be differences in procedures concerning death and the process of dying which the student need knowledge about.

4.7 Mental health issues

This area deals with mental health issues concerning the patient. The following subcategories involves mental health issues:

- The spiritual dimension
- Handling grief
- Quality of life
- Other emotional aspects of palliative care

4.7.1 The spiritual dimension

Several of the respondents reported that taking care of the patients religious beliefs were of great importance. The student has to consider how to organize the situation in order to attend to the patients' wishes and needs concerning this issue. Further the respondents reported that the students should give the patient the opportunity to talk to a clergyman or other relevant religious helper depending on the patients' religious background. Existential questions are often an issue for patients facing death, and the spiritual dimension often becomes more prominent than before.

”How to address the existential questions on the threshold of the unknown”.

In short, the student have to address the spiritual needs the patient might have.

4.7.2 Handling grief

It was stated by the respondents that both the patient and the relatives would experience grief in the process of facing death. When the patient is given the information that no treatment will be able to save his life, both the patient and the relatives might be overwhelmed with shock and grief. The students need to have knowledge about the different stages in this process, and know how to recognize the different phases.

”Knowledge about the patients expected reactions in regards to crisis and grief”.

The students have to be able to address the issue of grief in order to facilitate the situation for both the patients and their relatives.

4.7.3 Quality of life

Quite a few of the respondents expressed that the students have to be aware of the fact that quality of life is a significant issue also for patients who are dying. Even though there are no hope of being cured, there can be hope of having a good day, a good hour or maybe being able to attend to a loved ones birthday etc.

”Quality of life is a vital concept. The student can contribute to increased quality of life by creativity and making sure that the patient can experience life also outside of what goes on in the hospital”.

The use of humor and willingness to show happiness is mentioned as means to sustain quality of life.

4.7.4 Other emotional aspects of palliative care

The dying patients and their relatives are likely to experience strong emotions, which can take many forms.

”Emotional aspects of facing death”.

Anxiety is the most frequent reported emotion made out by the respondents, but also depression and uneasiness are mentioned. Some patients might experience cognitive failure and delirium as a consequence of their disease.

4.8 The concept of death

This area deals with the concept of death and what the students need to know about this issue. Subcategories are the following:

- Knowledge on the process of dying
- Practicalities concerning the deceased patient

4.8.1 Knowledge on the process of dying

The students need knowledge about the physical changes in the body in the last stage of life. What are the physical changes and processes , and what are the signs that tell the patient is about to die? For instance, marbling of the skin, respiration or gurgles.

“Knowledge about the last phase of life: what happens in the last days, hours, minutes. The bodily reaction to dying”.

The students need to know the expected phases the patient goes through the last 48 hours, and also the last few hours or the last minutes of life.

4.8.2 Practicalities concerning the deceased patient

The students need to have knowledge of what happens when the patient dies. Different rituals concerning death can be of importance to the relatives. How to care

for the body after the patient is dead is also an issue, there are strict guidelines for this last care.

”Procedures related to death”.

The students also need to know practicalities about what happens after the patient leaves the ward or the place the death has taken place. This is in order to help the relatives to find a funeral agency and give information on where the relatives can see the body.

4.9 Comparison of findings with White et al’s study

Throughout the thesis I have compared my study to White et als’ (2001) study, what follows is a comparison of findings and some final comments of the strengths and weaknesses on the two studies.

White et al (ibid) describes one of their aims to be to determine the educational needs in regards to palliative care. This coincides with the aim of my study, and is one of the main reasons why I chose to model on White et als’ study originally. White et al claims that their

[...]findings indicate useful information for nurse educators and practitioners about educational need of nurses providing EOL care” (White et al, 2001).

However, I believe that White et al’s findings has limitations when it comes to practical use of the findings. I will explain this in the following.

In White et al’s (ibid) study, they came up with twelve different areas. No elaboration of the twelve areas was done. This means that you have to assume that how each area is formulated actually reflects the understanding of what is viewed as the most important areas in regards to palliative care. Consequently, what is NOT expressed in this area is not viewed as important. For example, we know that ”How to talk to patients and families about dying” is the most important area from White et al’s (ibid) study, but what does this finding really say? This area coincides with my area of

”Interpersonal skills” that also deals with how to talk to patients and relatives. However, the area of interpersonal skills also contains several other related subjects, like general communication with the patients and relatives, not just restricted to talk about dying. The importance of listening, and the personal qualities and experiences of the students are also examples of what is discussed in the area of interpersonal skills. Common sense tells me that these issues are not viewed as irrelevant by the respondents in White et al’s (2001) study. From a scientific point of view, I claim that the lack of description and elaboration of the different areas in White et als’ study makes the findings to a certain degree limited when in comes to interpretative rigour and in-depth information about the area under study. It would be difficult to make use of their findings in practice. If someone were to make an educational program in palliative care based on the findings of White et al’s (2001) study, they would actually have to guess the content of the different areas based on one sentence.

In comparison, I believe that the main strength in my study compared to White et al’s (ibid) study is the description and elaboration of each area, which reflects the views of the respondents in terms of the broad content of each area. This makes it useful for practice and the findings can provide strategies for optimizing the nursing education in regards to palliative care. Comparisons of White et al’s (ibid) findings and mine are problematic due to the differences in how the areas are described. My seven main areas are broad and covers several issues, White et al’s twelve areas covers less, and is more specific. The only area in White et al’s (ibid) study not covered in mine is the area of ”dealing with angry patients and their families”. I want to point out that White et al’s study also emphasize the importance of ”dealing with your own feelings”, which was included as part of ”personal qualities and experiences”, and assessed as a valuable contribution in my study, as discussed in the previous chapter.

When it comes to the findings regarding the statistics when presenting the data, White et al’s (ibid) study has strengths. Because all of the respondents ranked the same areas, the validity of the quantification is higher than in my study. I had to make some decisions that could have an impact on the results in terms of the rankings. I split up the answers, and related to the new number of answers. Some of the respondents

didn’t rank their answers, and this was a problem when making the tables that showed how many said what. However, I believe that the quantification of my data is valid in the sense that it does what it intends to do. It gives an overall picture of the answers of the respondents, and because of the tables made from the quantification of data, it is easier to get a sense of the whole in this study.

5. Discussion

5.1 Discussion of findings and implications for practice

In this chapter I will discuss and compare the findings in my study to previous studies, primarily based on the studies described in the literature review. I will also discuss what the issues in why students don't feel prepared are, and how knowledge about this can have implications for practice.

5.1.1 Comparison of findings with existing literature

The Norwegian educational program described in the literature review focused on the following main areas:

- Values and thinking within hospice philosophy
- What is palliative care?
- Lifetime perspective and understanding the last phase of life
- Soothing of pain, suffering and comfort
- Fatigue and the consequences for everyday life
- Nursing and a dignified death
- Loss, grief and hope
- Ethical considerations linked to the framework conditions for hospice philosophy

The role of hospice philosophy is essential in this particular nursing school, and this might color the choice of areas tutored. Hospice philosophy is an area mentioned by respondents in my study as well. It is a subcategory in the area of ”knowledge on palliative care”. It is however, not as highly emphasized by the respondents in my study, as it seems to be in this educational program. However, it was the nurses who work in hospices that stated hospice philosophy as an area, and the rankings were

high. These nurses must be said to be extremely information rich, and the fact that they claim hospice philosophy as a very important area the students need to learn about should be taken seriously, even though there are just a few statements of this.

”Fatigue and the consequences for everyday life”, was not highly emphasized in my study. Fatigue was mentioned once, and consequences for everyday life were not an area of discussion and neither was ”life time perspective”. Apart from that, several of the areas coincide with the findings in my study. They have different formulations, but deals with similar subjects. For example ”soothing of pain, suffering and comfort” coincide with the areas of ”pain” and ”symptom management”. ”Loss, grief and hope” coincide with the area of ”mental health issues”. Nursing and a dignified death can be linked to the areas of ”knowledge on palliative care” (nursing) and ”interpersonal skills” (dignified death). However, the subcategory of personal qualities and experiences in the students, are not addressed in this program, which is interesting as this is one of the most emphasized categories in my findings.

The review of a Nordic textbook (Kaasa, 2007) was mentioned in the literature review, and I would like to go in further details on this book and compare the findings. The reason why I choose to do this, is that the format of a textbook gives an overview of all the areas that are viewed as important in much greater detail than a listing of the subjects dealt with in an educational program can do. I have an extensive amount of data that also give detailed information about what the respondents view as important areas, which gives a good basis for comparison. This textbook is curriculum in several of the bachelor nursing educations in Norway and consequently very relevant for mapping out what is viewed as important areas in the nursing education today.

The main areas covered in this book are the following:

- What is palliative care?
- The patient and the relatives
- Organization and systems for subsidies

- Pain and treatment of pain
- Other symptoms and conditions

(Kaasa, 2007)

There are 41 chapters in this book, to cover these five main areas. I will not list the content of all the chapters, just make statements about the differences and similarities in this book and my findings. The five main areas are all reflected on in the findings in my study. Of the 41 different chapters, four chapters dealt with areas not covered by the respondents in my study. These four areas were research in palliative care, palliative care in an intensive care unit, molecular genetics and medicamental treatment of pain to the elderly. When it comes to the problem of discussion, what does nursing students need to learn about through the nursing education, it is even more interesting and relevant to look at this the other way around. What areas stated by the respondents that are NOT covered by the textbook. It turns out that all of the eight main areas are covered in the textbook in some way or the other. From the 25 subcategories, all but two are covered. This is ”personal qualities and experiences” and ”hospice philosophy”. Interestingly enough, this means that one of the biggest, and also the smallest category in terms of quantification are not an issue in the textbook. Personal qualities and experiences are highly emphasized among the respondents, and a lot of the answers deal with attitudes towards death and how to handle their own reactions when encountering dying patients. The lack of emphasis on this in the textbook is a very interesting point I will come back to later in this chapter.

The findings in this study will also be compared to the ELNEC program that was mentioned in the literature review. The areas listed in this program have, as previously mentioned, been used as guide lines for education in palliative care, both when it comes to development of special educational programs and also for the choice of topics in textbooks. Hence, it is relevant to compare the findings in my study to these areas.

ELNEC listed nine areas of importance when teaching palliative care, these will be listed in detail to have better basis for comparison:

- Nursing Care at the End of Life: Overview of death and dying in America, principles and goals of hospice and palliative care, dimensions of and barriers to quality care at EOL, concepts of suffering and healing, role of the nurse in EOL care.

- Pain Management: Definitions of pain, current status of and barriers to pain relief, components of pain assessment, specific pharmacological, and non-pharmacological therapies including concerns for special populations.

- Symptom Management: Detailed overview of symptoms commonly experienced at the EOL, and for each, the cause, impact on quality of life, assessment, and pharmacological/non-pharmacological management.

- Ethical/Legal Issues: Recognizing and responding to ethical dilemmas in EOL care including issues of comfort, consent, prolonging life, withholding treatment; euthanasia, and allocation of resources; and legal issues including advance care planning, advance directives, and decision making at EOL.

- Cultural Considerations in EOL Care: Multiple aspects of culture and belief systems, components of cultural assessment with emphasis on patient/family beliefs about roles, death and dying, afterlife, and bereavement.

- Communication: Essentials of communication at EOL, attentive listening, barriers to communication, breaking bad news, and interdisciplinary collaboration.

- Grief, Loss, Bereavement: Stages and types of grief, grief assessment and intervention, and the nurse's experience with loss/grief and need for support.

- Achieving Quality Care at the End of Life: Challenge for nursing in EOL care, availability and cost of EOL care, the nurses' role in improving care systems,

opportunities for growth at EOL, concepts of peaceful or "good death", "dying well", and dignity.

- Preparation and Care for the Time of Death: Nursing care at the time of death including physical, psychological, and spiritual care of the patient, support of family members, the death vigil, recognizing death, and care after death

(American Association of Colleges of Nursing (AACN), 2009)

Except for the matter of overview of death and dying in America, which of course not would come up as an issue in a Norwegian study, and the matter of achieving quality care at the end of life, with emphasis on the nurses role in improving care systems, all of the areas listed by AACN are in some way or another mentioned by the respondents in my study. And the other way around, the areas and subcategories listed in my study are all covered by the areas in the ELNEC program in some way.

As a summary I wish to state again what I said in the beginning of this chapter. Both the literature review and this comparison show that the areas made out as important in palliative care to a great extent coincide in the different educational programs. Interestingly enough, it also coincides with what the respondents in my study say are important areas. Thus, my findings support existing literature when it comes to what nursing students should learn about palliative care. Accordingly, I make a general assumption that educational programs in most cases address the actual issues that are viewed as important in palliative care. This is a very important finding that raises new questions. So why is it not working?

Why does so many studies describe how the students feel unprepared to carry out palliative care, if the educational programs to all appearances address these vital issues? With the basis of the findings in my study, I believe that it is of the utmost importance to discuss these questions.

The aim of this study is to identify important areas for nursing students to learn about through the nursing education. The overall aim of the study is to give information that can provide strategies for optimizing nursing education and in this way help the

nursing students to be better prepared to carry out palliative care. I have addressed the first part of this aim by analyzing the answers given by the respondents, identified areas, and presented them in a way that gives an overview of the important areas in palliative care. Because the comparisons made with the educational programs show that the students in all likelihood for the most part are taught the things viewed as important, it is necessary to address the questions raised from these findings, in order to comment on how to provide strategies for optimizing nursing education and help the students be better prepared to carry out palliative care.

There are several different potential explanations to why the students still feel unprepared to carry out palliative care even though the important issues are addressed in the education. Does it have to with teaching methods? How the education is organized? The gap between theory and practice in nursing have been highly emphasized and studied in numerous articles and textbooks (Gennaro S, 2003; Rolfe, 2001; Swain J, 2003). To discuss this further in regards to palliative care would be a valuable approach. In connection to this it would also be interesting to discuss to what extent the students actually acquire the knowledge they are taught in the nursing education and how they transfer this knowledge into practice. All of these are interesting questions when discussing why nursing students don't feel prepared to carry out palliative care.

However, I wish to discuss this issue with a basis in my data, as I believe it contains findings that to a great extent can explore why the students still feel unprepared. In the following I will give an account of the relevant findings in my study that can explore this issue.

5.1.2 Personal qualities and experiences

The area of interpersonal skills was the largest area in terms of quantification, all together 203 answers dealt with this area. Within the area of interpersonal skills, there were two subcategories, "communication and interaction" and "personal qualities and experiences". Of the 203 answers in this area, 78 answers dealt with personal

qualities and experiences. The number of answers in this subcategory reflects the high emphasis on personal qualities by the respondents in my study. The area of "personal qualities and experiences" has been elaborated on in the presentation of findings, section 4.2.2. page 65. As a brief summary, the area deals with the qualities within the students in regards to values and attitudes, and the impact on the students' experiences with death and dying. It also deals with students' death anxiety and the importance of taking care of oneself when dealing with dying patients. This area stands out as interesting when discussing why the present education seems inadequate in preparing the students for palliative care. The reason for this is two-folded: this is the only area not emphasized in the education, and also it can be claimed that it is the area that is the most difficult to teach, as it deals with the students own personality and experiences. I will elaborate on this later. In short, one of the largest findings in my study is the one that is addressed the least in the nursing education as well as it might be the most difficult to teach in the first place. There is a gap here that I will discuss in the following.

The category of "personal qualities and experiences" can be said to be important in all aspects of nursing. The use of oneself as a person has deep impact on the patient-nurse/student relationship. This is highlighted by Barbara Carper (1978) in her theory on "fundamental patterns of knowing in nursing". Carper describes four different patterns of knowing designated as empirics, esthetics, ethics and personal knowledge. According to Carper (ibid), the component of personal knowledge is the most problematic and the most difficult to master and teach. She describes the term personal knowledge to concern "the knowing, encountering and actualizing of the concrete, individual self". By this I understand that she recognizes the importance of the nurse as a person in the nurse-patient relationship, and how personal qualities impact on how the nurse deals with the patient. She use the term "therapeutic use of self" to illustrate this and claims that the way in which nurses view their own selves and the patient, is of primary concern in the nurse-patient relationship (ibid). This has transfer value to the student-patient relationship in palliative care. The student encounters the patient not only as a product of what they have learned in the nursing

education, but also as a person with personal qualities, values and attitudes. Carpers' (1978) theory deals with all aspects of nursing. Based on the findings in my study, I believe that the component of personal knowledge is especially important in palliative care compared to other aspects of nursing. The extraordinary issue in palliative care is that it deals with death on a regular basis, and that death is the outcome for the patients without any hope of cure. The reason why this is an issue, is that death in itself is a concept very difficult to grasp. The literature review explores how death anxiety is an issue for nursing students and how it should be addressed in the nursing education (Dickinson, 2007; Kurz & Hayes, 2006; Lockard, 1989). The thought of ones own mortality comes to mind when facing death in patients, and there are a great deal of taboos around this issue, which can impact on the level of death anxiety.

According to O'Brien (1993) the fact of our individual and collective mortality might be the single most important and widely held taboo in our society. This is a subject many people find extremely difficult to consider, and health personnel are not immune from this phenomenon. To explore why this is, a glance back in time is in order. According to Katz (1998) the social organization of death underwent radical changes in the early part of the twentieth century. Before this period of time, death occurred for the most part in peoples' homes, within all age groups. All people, regardless of age, were exposed to death and dying at home. Throughout the twentieth century it became more and more common that caring for dying patients were the responsibility of the hospitals and death was no longer commonly observed by different generations in peoples home. At the same time, extensive progress was made in medicine, making death associated with old people, rather than something likely to occur at any stage of life (ibid). Death became less of a natural part of life than earlier, and this is the starting point for the students today. I believe this has consequences for why nursing students find it so difficult to be prepared when carrying out palliative care.

O'Brien (1993) also states that if health personnel have major unresolved issues concerning their own mortality, it is unlikely that they will be able to truly stand

alongside those who are facing their own imminent death. (ibid). The fact that there are so many mysteries and taboos concerning death will have a great impact on how the students deal with caring for dying patients. This is emphasized in my study as the respondents underline the importance of the student as a person in palliative care, and how their own values and attitudes impact on how they relate to it. If taboos around death are as extensive as described by O'Brien (1993), it is likely that the students experience this area of death and dying as extremely difficult to face to begin with. The students are shaped by the society in which they are raised, and will enter the nursing role with the same taboos and attitudes that colors everyone else. There will always be individual differences in attitudes and how to handle taboos, also among nursing students. Some handle it well, and some think it's extremely difficult. My assertion is however, that because of the extensive degree of taboos in the society, death is most likely more difficult to handle for the nursing students than all other aspects of nursing. This should be viewed as a starting point when organizing the education in palliative care, but instead it seems that this is overlooked in the education by not being addressed as an issue. As described in the literature review Dickinson (2007) claims that death anxiety issues are shaped during students initial educational programs, and it is therefore important to recognize and confront their own reactions to death in training.

O'Brien (1993) claims that when discussing taboos, attitudes are the essential concern. A basic change in attitudes is required if we are to stop viewing patients with incurable illness as some kind of medical failure. This is supported by Katz (1998) in her exploration of how death has been "medicalised" progressively over the last decades. The focus of the hospitals has shifted from caring to curing, as a consequence of medical advances and extensive research, and this is the origin of the view of death as a medical failure. Studies by Glaser and Strauss in the sixties concluded that there were a discrepancy between the way health personnel interacted with persons likely to survive and patients expected to die (Katz, 1998). Dying patients had lesser contact with health personnel. Later studies have concluded somewhat similar: Because of the fact that death is viewed as a failure of the medical

system, it is also a reflection of failure of the health personnel. Because of this, health personnel aims to protect themselves by planning communication with dying patients in such a manner that discussion about death and dying is kept to a minimum. Discussion about death and dying was seen as a source of emotional distress for the health personnel (Brechin, 1998) I believe it's important that the students view death as a natural part of life to avoid this kind of thinking. When death is considered a failure, the whole idea of palliative care goes against what we are used to think the health care system is about. This can also shed light on why nursing students find it hard to encounter dying patients in the first place.

As described in the literature review, a great deal of the different educational programs follows guidelines from the ELNEC program made out by AACN. Even though different terminology is used, the core areas seem to coincide with the different areas in the ELNEC program.

This raised some questions. Is it a good thing that so many programs seem to base their tutoring on AACN's core areas? Is this an indication that AACN actually have found the most important areas in palliative care and therefore the ELNEC program should be used as a basis to make the best possible educational program? Or is it the other way around? For example, the fact that so many programs follow the same guidelines might be part of the problem why nursing students feel so unprepared to carry out palliative care. Maybe this is not working in the first place?

The ELNEC program has, as previously mentioned, been evaluated as an "extremely successful" program that showed significant improvements in the knowledge level in the students. Based on the previously discussed issue of the importance of personal qualities and experience, I question the fact that the program can be evaluated as "extremely successful" when the basis for the evaluation is measures in knowledge level. Because of the complex problem of dealing with death, I believe there is a difference between being prepared and feeling prepared. This was also discussed in section 1.1.2 page 12. A high level of knowledge might not be enough for the students to feel prepared. They also need to be able to cope with the issue of death on

a personal level. My findings suggest that this is crucial for whether the students feel prepared or not. However, the strength of the ELNEC program could be this point exactly. AACN argues that one of the key success factors of the ELNEC program is that it addresses the issue of death.

“People in our country deny death, believing that medical science can cure any patient. Death often is seen as a failure of the health care system rather than a natural aspect of life. This belief affects all health professionals, including nurses. Despite their undisputed technical and interpersonal skills, professional nurses may not be completely comfortable with the specialized knowledge and skills needed to provide quality palliative care to patients. The ELNEC project gives nurses the knowledge and skills required to provide this specialized care and to positively impact the lives of patients and families facing the end of life.” (American Association of Colleges of Nursing, 2009)

My assertion from this is that the ELNEC program might be an extremely successful program in many ways, they approach both the knowledge issues, and the issue of death. However, the evaluation of the program that came to this conclusion might have concluded on limited grounds, as it only measures the knowledge level of the students. As described in the literature review, Kurz and Hayez (2006) studied death anxiety in nurses who attended an ELNEC program. This group of participants is more likely to have more experience in coping with death than the students as a group. However, the study has transfer value as it deals with the ELNEC program, and the issues are the same whether or not you are a nurse or a student. Kurz and Hayez (ibid) concluded that the program had a positive effect on death anxiety in the short run, but that the results were not long lasting. The authors suggest that it is necessary to repeat the program to optimize the effect. Barrere et al (2008) concluded similarly in their study on changes in attitudes after attending an ELNEC program, the program needed integration throughout the nursing education. This has implications for this study as well. If the effects of the education program only have short-term effect on death anxiety and attitude changes, this would be an argument for continuously addressing this issue throughout the education. The different studies

on death anxiety, which is accounted for in the literature review, give a picture of how both educational programs and experience has an impact on death anxiety. This is yet another argument why students feel so unprepared in the field of palliative care. The preceding discussion implies that carrying out palliative care involves dealing with your own death and death anxiety. Clinical experience has an impact on death anxiety and change of attitudes toward death. (Barrere, Durkin, & LaCoursiere, 2008; Kurz & Hayes, 2006). Consequently it might be difficult for inexperienced students to deal with death and death anxiety, and carry out palliative care. The educational program is not enough. First of all, there seem to be little focus on the issue of death anxiety in the current educational programs. This leaves the students with knowledge of different aspects of palliative care about how to treat the patient, but limited information on how to deal with their own death anxiety. Secondly, even though the students are involved in an educational program that actually deals with this issue, it is still not enough. Clinical experience also has an impact on how to deal with death and death anxiety. Based on these assertions, I suggest the best way of preparing the students for carrying out palliative care may be by iteratively repeating a specialized education program throughout the nursing education.

The introductory chapter describes how The Ministry of Health and Care Services (Helse- og omsorgsdepartementet, 2006b) claims that the government aims to enhance the competence in palliative care. If this goal is to be taken seriously, it seems necessary to develop a common educational program in palliative care to be integrated in all Norwegian nursing schools as a specific part of the over all plan. This as opposed to today's overall plan which only states that the students need competence in how to "relieve suffering and help the patient to a dignified death", but does not give any elaboration on how to achieve this goal. A potential common national educational program in palliative care should address both issues in caring for the patient, as described in the chapter of findings, as well as issues in the students themselves, in regards to personal qualities, attitudes toward death and death anxiety. This program needs to be implemented in different stages of the education, for example by undergoing different phases of the program repeatedly in all three years. Throughout the education the students will have extended experiences from practice

to make use of when learning about palliative care. By iteratively addressing the issue of palliative care, the students will both be better prepared when they encounter palliative patients in the practice field, and they will also be able to relate to practical experiences when acquiring theoretical knowledge about the issue.

As a summary the implications for practice in this study is the suggestion that the nursing education should contain an opportunity for the students to iteratively undergo an educational program in palliative care. Additionally the students need multiple opportunities for clinical experience throughout the education. Combined this would give an opportunity for the students to be better prepared in terms of knowledge, as well as to feel better prepared in terms of dealing with death and dying.

From this discussion of findings and implications for practice, I turn to discussing comparisons between the three respondent groups followed by a discussion of comparing my study to White et al's (2001) study.

5.2 Comparison of findings between the three respondent groups

One of the research questions raised to begin with was the following: ”What are the differences and/or similarities between what the different groups of respondents say about the important areas for nursing students to learn about in palliative care?”

The different roles the different respondent groups play in regards to palliative care makes this an interesting question. They each have expert opinions in their respective fields. The nurses are experts on how to carry out palliative care in practice, and it is fair to believe that they are in a position to judge what areas in palliative care that are important to learn about. The students may not be able to judge this with the same professional expertise as the nurses, but they do have expertise in the field of knowing what it's like to be a student and what they need to feel prepared to carry out palliative care. The teachers who teach palliative care on a regular basis are expected

to know what they teach and how, and will be able to contribute knowledge about what the important areas in palliative care are.

These three respondent groups are a result of maximum variation sampling strategy. As explained in the method chapter, the strength of maximum variation is that patterns that emerge from this strategy complies with a lot of people in a heterogeneous group and is consequently of particular interest. Similarities among the three respondent groups will yield strong findings in what is viewed as important areas in palliative care. In the contrary case it is interesting to discuss possible differences and possible explanations to why the findings yield differing results in the three respondent groups.

As described in the analysis chapter, the main areas found in each of the respondent groups seemed quite different initially. However, in the analysis process it turned out that the main areas were somewhat the same in all the three groups. Consequently, I assess that the main areas identified in this study to a great extent are valid findings as they comply with all respondent groups with small differences. There were however, differences in which area were viewed as more important among the three groups, and also differences in some of the subcategories. The teachers stated fewer areas than the nurses and the student. The two areas that were not stated by the teachers were ”the concept of death” and ”pain management”. Pain management was one of the largest areas in the other two groups, so this is a significant difference in findings. Pain was mentioned also among the teachers, but there were great differences in the way they argued that this was an important area. For the teachers, pain was only listed as part of other symptoms, and didn’t really stand out as a separate area, and this was very different from the nurses and the students who expressed that pain was one of the most important areas. Among the students, the largest area was pain management. It’s interesting that the students understand pain management to be the most important area. Does this finding indicate that this is what the students feel are the most important issue for the patient, or is it an indication of what the students are most scared of facing when encountering dying patients? These questions made me think there are two ways of interpreting this finding. The obvious reason is that this

area stands out as most important out of concern for the patient. Relieving of pain is of utmost importance for the well being of the patient, and the fact that the students view this as the most important area might be an acknowledgement of their responsibility towards the patient. However, it might also reflect the students' attitudes toward death and dying as a process filled with pain and suffering. Death is often portrayed as scary and painful, both in books, movies and other media and this might be the general attitude of death the students start out with. I see this in comparison to the previously discussed issues of taboos and attitudes toward death. The area of interpersonal skills was listed the most frequent among both the nurses and the teachers. Among the students, it was listed the second most frequent. Rankings did not vary a lot among the respondent groups. The students average ranking was 2.60, the teachers ranked this area as 2.75, whereas the nurses ranked it as 2.84. The subcategories were the same in all the respondent groups. The three respondent groups combined give a view of this area as the most important all together. There were however, slight differences in the emphasis in the subcategories. Both the nurses and the students had a considerable higher emphasis on the subcategory of communication and interaction, whereas the teachers had the same emphasis on personal qualities as the category of communication and interaction. The biggest difference between the groups where the issue of how they actually described this area. The nurses were more likely to describe how to communicate, and how to interact, whereas the students would state that communication and interaction in fact was important. An example of what a nurse answered is as follows:

"To be able to communicate in a good manner. You have to be aware of non-verbal communication. A significant part of communicating with palliative patients is to listen. You have to take what the patient says seriously and respect the patients' wishes. To be able to talk about death in a natural way is also important".

Many of the nurses' answers were similar to this. The students answered more typically like the following:

"How to communicate with dying patients and their relatives".

The teachers on the other hand, were to a great extent interested in holistic thinking, were the emphasis on the relatives were more distinct than in the other two groups. They also focused on the education itself. An example of how the teachers answered:

”Communication. The teaching should be linked to how to encounter dying and seriously ill patients. Communication with relatives is also important”.

When it comes to the area of symptom management, there were also severe differences among the teachers and the two other respondent groups. How the teachers talked about the symptoms were different from the other groups. They were very concerned with the fact that it was vital for the student to know how to observe the symptoms and act on the basis of what they observed. Picking up on the patients’ cues was their main focus. The students and nurses were mostly preoccupied with what they needed knowledge about in regards to symptom management. From appendix VI-VIII it’s possible to see the differences in emphasis among the three groups. 6 out of 21 answers from the teachers dealt with observation, whereas 4 of 95 and 1 of 24 of the students regarded observation as an important area in symptom management.

For more detailed overview of all the areas and how the respondents listed and ranked them, see appendix VI-VIII.

As a summary I would say that even though there are some differences among the three groups, the similarities are much more prominent, this supports the validity of the findings.

6. Summary and conclusion

Studies internationally and anecdotal evidence from Norway as well as personal experience provided the rationale and inputs of this project. Nursing students express that they feel unprepared to carry out palliative care. Nursing education seems insufficient in preparing the students to do this kind of work. In response this study aimed to identify important areas in palliative care for the students to learn about through the nursing education in Norway. The method for collecting data was through a survey with an open-ended question: “What areas do you see as important for nursing students to learn about through the nursing education when it comes to palliative care?” Data was collected from three respondent groups; nursing students, nurses and teachers of palliative care. Analysis of the data yielded seven different areas the respondents identified as important for nursing students to learn about:

- Interpersonal skills
- Symptom management
- Pain management
- Knowledge on palliative care
- Contextual conditions
- Mental health issues
- The concept of death

There were quite a few similarities among the three different respondents groups in terms of what areas they viewed as important. Most of the differences were concerning what they emphasized in the different areas, and the subcategories differed to a small degree among the respondent groups. For an overview of all the areas and subcategories, see table 8 page 62.

Interpersonal skills were the area most frequently emphasized by the respondents. The answers were concerning the relationship between the student and the patient with their relatives. Communication and interaction were of focus in this area, as well

as personal qualities and experiences and the students' ability to deal with death and dying. How to manage different symptoms was also a highly emphasized area. Among the nurses and the students the area of pain was extensively emphasized to such a degree that it emerged as a separate area. General knowledge about palliative care was also viewed as important, as well as the impact of contextual conditions, like legal and timely issues. Interdisciplinary cooperation was identified as an important factor in contextual conditions that impact on the patients' life by giving the patient the opportunity to have different needs not related to nursing met by a professional. Relating to the patients' mental health in terms of grief and the spiritual dimension are also viewed as important. Of the areas identified as important, the one receiving the least emphasis was knowledge about the concept of death, which included the process of dying and the practicalities concerning the deceased patient. These results were used to reach the aim of the study of providing strategies for optimizing the nursing education in regards to palliative care. Discussions concerning the above mentioned findings revolved around the following:

- Comparison of findings with existing literature
- Potential explanations for inadequate preparation of nursing students with respect to palliative care
- Implications for practice

The findings were compared to subjects addressed in different educational programs and textbooks to be able to comment on the potential gap between my findings and the educational programs offered to the students. This comparison showed two things: Areas dealt with in different educational programs coincide extensively. These areas also coincide with what the respondents in my study identify as important areas. Thus, my findings support existing literature when it comes to what nursing students should learn about palliative care. The different educational programs addressed a lot of the same issues, and my findings coincided extensively with these subjects addressed in the educational programs. From these findings, questions were raised. Why then, does the students' still feel unprepared to carry out palliative care? If the areas viewed as important are the areas actually taught, then

what's the problem? My data gave potential explanations to this. There was one area that to a very small degree was focused on in the education: the area of personal qualities and experience. This involves the student as a person and how to deal with death and dying. Discussion concerned how the students are shaped by society in terms of taboos around death and the attitudes that comes with the assumption that death is a failure of the health care system instead of a natural part of life. Before the students can deal with this on a personal level, it will be very difficult to deal with dying patients, and the students might feel unprepared because of this. Strategies to optimize the nursing education with a basis of my findings indicate that the issue of death and dying and death anxiety need to be addressed and dealt with early in the education and continuously throughout the education. We need more information about whether teaching methods and organization of the education have an impact of this, as the literature review show that clinical practice also has an impact on the ability to carry out palliative care. A suggestion is to develop a common national educational program that address both issues in caring for the patient, as well as issues in the students themselves, in regards to personal qualities, attitudes toward death and death anxiety. Such a program should be implemented repeatedly in different stages of the education. In addition the students must be given multiple opportunities for clinical experience throughout the education. Combined this would give an opportunity for the students to be better prepared in terms of knowledge, as well as to feel better prepared in terms of dealing with death and dying. In other words, more prepared than scared.

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Appendix I Reply from Norsk Samfunnsvitenskapelig Datatjeneste

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Julianne Cheek
Institutt for sykepleievitenskap
Universitetet i Oslo
Postboks 1153 Blindern
0318 OSLO

Vår dato: 05.11.2008 Vår ref:20132 / 2 / KH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 03.10.2008. Meldingen gjelder prosjektet:

20132	*Kjerneområder innen lindrende behandling*
Behandlingsansvarlig	*Universitetet i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Julianne Cheek*
Student	*Camilla Hardeland*

Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektopplegget endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig. Prosjektet kan settes i gang.

Vennlig hilsen

Bjørn Henrichsen Kjersti Håvardstun

Kontaktperson:Kjersti Håvardstun tlf: 55 58 29 53
Vedlegg: Prosjektvurdering
Kopi: Camilla Hardeland, Langøyveien 71a, 1679 KRÅKERØY

Personvernombudet for forskning

Prosjektvurdering - Kommentar

20132

Det opplyses i meldeskjema at spørreskjema vil være i papirformat. Eventuelle indirekte personidentifiserbare opplysninger som kjønn, fjernes eller kategoriseres tilstrekkelig ved manuell registrering på pc, slik at datamaterialet som behandles på pc kun foreligger i anonymisert form. Ikke-sensitive opplysninger som kun behandles manuelt er ikke omfattet av meldeplikt.

Med anonyme opplysninger forstås opplysninger som ikke på noe vis kan identifisere enkeltpersoner i et datamateriale, verken direkte gjennom navn eller personnummer, indirekte gjennom bakgrunnsvariabler eller gjennom navneliste/koblingsnøkkel.

Ombudet anbefaler at følgende setning i informasjonsskrivet til utvalget utgår: "Alle svar behandles og lagres anonymt", og erstattes med følgende: "Datamaterialet anonymiseres og spørreskjema makuleres innen prosjektslutt 12.06.09".

Appendix II Example of application to access the field

Camilla Hardeland
Kontaktinfo Dato

XXX Sykehjem

SØKNAD OM TILLATELSE TIL Å GJENNOMFØRE MASTERGRADSPROSJEKT OM LINDRENDE BEHANDLING VED XXX SYKEHJEM.

Jeg er masterstudent ved Universitetet i Oslo, Institutt for sykepleievitenskap, og arbeider for tiden med min masteroppgave, der jeg er tilknyttet et samarbeidsprosjekt kalt ”Praksis som læringsarena”. Dette er et samarbeid mellom xxx kommune, xxx kommune, xxx kommune, xxx kommune, xxx kommune og Høgskolen i xxx, der xxx Sykehjem også er en av aktørene. Prosjektet omhandler blant annet lindrende omsorg og behandling, noe som også er tema for mitt prosjekt. I den forbindelse henvender jeg meg nå til dere for å søke om tillatelse til å gjennomføre deler av mitt prosjekt ved deres virksomhet.

Prosjektet har til hensikt å identifisere viktige områder innenfor lindrende behandling for slik å kunne konkretisere hva man bør vektlegge i sykepleierutdanningen når det gjelder dette temaet. Bakgrunnen for å gjøre dette er at mange sykepleierstudenter har gitt uttrykk for at de føler seg nervøse og uforberedt til å utføre lindrende behandling, og undervisningen oppfattes som mangelfull både i innhold og omfang. Ved hjelp av dette prosjektet håper vi å kunne forbedre utdanningen for slik å gjøre sykepleierstudentene bedre forberedt på å utføre denne type sykepleie. For å få flere ulike perspektiver på temaet, er både sykepleiere, studenter og høgskolelærere forespurt om deltakelse i prosjektet.

Det er ønskelig å ta i bruk alle sykehjemmets sykepleiere som respondenter. Datainnsamling vil foregå ved hjelp av et spørreskjema der det vil bli stilt ett enkelt spørsmål med åpne svaralternativer. Det forventes at det tar ca. 10-15 minutter å svare på spørreskjemaet. Jeg håper det er mulighet for å gjennomføre spørreundersøkelsen i virksomhetens lokaler i de ansattes arbeidstid, gjerne i forbindelse med en kursdag, dersom dette er aktuelt.

Undertegnede er underlagt taushetsplikt og vil være den eneste som har tilgang til innsamlede spørreskjema. Disse vil makuleres når prosjektet avsluttes, i august ’09. Alle svar behandles og lagres anonymt. Masteroppgaven skrives i artikkelform, og vil gjøres tilgjengelig for Peer Gynt Sykehjem etter ferdigstillelse i juni ’09.

Prosjektet er meldt til Personvernombudet for forskning ved Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Jeg håper denne henvendelsen gir tilstrekkelig informasjon for at dere skal kunne vurdere min søknad.
Ved eventuelle spørsmål, ta gjerne kontakt på tlf 92 45 39 00 eller pr. e-post camilla.hardeland@gmail.com

Med vennlig hilsen

Camilla Hardeland
Masterstudent UiO

Veileder: Professor Julianne Cheek

Appendix III Search history

Cinahl:

1 Students, nursing / or students, nursing, baccalaureate
2 Education, nursing
3 Death Education
4 Palliative Care / ed [Education]
5 Terminal Care / ed [Education]
6 1 OR 2
7 3 OR 4 OR 5
8 6 AND 7
9 Limit 8 to (English and yr="2000 – 2009")

74 hits

Medline:

1 Students, nursing
2 Education, nursing
3 Death
4 Palliative Care
5 Terminal Care / ed (Education)
6 1 OR 2
7 3 OR 4 OR 5
8 6 AND 7
9 Limit 8 to (English language and yr="2000 – 2009")

70 hits

Embase:

1 Nursing Student
2 Nursing Education
3 Death Education
4 Palliative Therapy
5 Terminal Care
6 1 OR 2
7 3 OR 4 OR 5
8 6 AND 7
9 Limit 8 to (English language and yr="2000 – 2009")

44 hits

ERIC:

1 Students, Nursing
2 Education, Nursing
3 Death Education
4 Palliative Care
5 Terminal Care
6 1 OR 2
7 3 OR 4 OR 5
8 6 AND 7
9 Date range 2000 – 2009

5 hits

LINDRENDE BEHANDLING

HVA TRENGER SYKEPLEIERSTUDENTER Å LÆRE?

CAMILLA HARDELAND

FORESPØRSEL OM DELTAKELSE I PROSJEKT OM LINDRENDE BEHANDLING

Du blir herved forespurt om å delta i en spørreundersøkelse som er en del av et mastergradsprosjekt ved Universitet i Oslo, Institutt for Sykepleievitenskap og Helsefag. Prosjektet har til hensikt å identifisere viktige områder innenfor temaet lindrende behandling.

Lindrende behandling defineres av Verdens helseorganisasjon som :
"Aktiv behandling, pleie og omsorg av pasienter med en inkurabel sykdom og kort forventet levetid."

Bakgrunnen for å gjennomføre dette prosjektet er at mange sykepleierstudenter har gitt uttrykk for at de føler seg nervøse og uforberedt til å utføre denne type sykepleie, og undervisningen oppfattes som mangelfull både i innhold og omfang. Ved å identifisere hvilke områder som er viktige innen dette temaet, vil det være mulig å forbedre undervisningen for slik å gjøre sykepleierstudentene bedre forberedt på å utføre lindrende behandling.

For å få flest mulig ulike perspektiver på temaet, er både sykepleiere, studenter og høgskolelærere innlemmet i prosjektet. Deltakelse i prosjektet er frivillig og det får ingen konsekvenser dersom du velger å la være å svare. Utfylling og retur av spørreskjema anses som samtykke til deltagelse i prosjektet. Undertegnede er underlagt taushetsplikt og vil være den eneste som har tilgang til innsamlede spørreskjema. Disse vil makuleres når prosjektet avsluttes, i august '09. Alle svar behandles og lagres anonymt. Prosjektet er meldt til Personvernombudet for forskning ved Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Ditt bidrag til dette prosjektet er å fylle ut det vedlagte spørreskjemaet. Her blir du bedt om å liste opp ulike områder det er viktig å ha opplæring i gjennom sykepleierutdannelsen når det gjelder lindrende behandling. Det kan oppgis inntil 5 ulike svar. Deretter skal svarene rangeres etter viktighet.

Det finnes ingen fasitsvar på hva som defineres som et "område" ved utfylling av skjema. Det kan være alt fra en liten detalj til mer omfattende kunnskap, og hentes fra både teori, praksis eller andre erfaringer. Det viktigste er at du tenker deg godt om og gir konkrete eksempler på hva du oppfatter som viktig. Skriv gjerne i stikkordsform, men det settes pris på om du utdyper ytterligere hva du mener.

Dersom du har noen spørsmål, ta gjerne kontakt med undertegnede på
epost: camilla.hardeland@gmail.com eller tlf.nr. 92 45 39 00

På forhånd tusen takk for at du tar deg tid til å være med på dette prosjektet.

Med vennlig hilsen

Camilla Hardeland
Masterstudent UiO

Alder: _____

Kvinne: _____ Mann: _____

"Hvilke områder anser du som viktige å ha opplæring i gjennom sykepleierutdanningen når det gjelder lindrende behandling?".

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Etter å ha listet opp de ulike områdene, vennligst ranger svarene i prioritert rekkefølge fra 1 til 5 i boksen ved siden av svaret ditt, fra hva du syns er mest viktig til hva du syns er minst viktig. 1 er mest viktig, deretter 2, 3 og 4 fram til 5 som er minst viktig. Har du færre enn 5 svar, starter du fortsatt på 1 (mest viktig) og rangerer så mange svar du har.

Appendix V Example of analytical process

Original answer	Original ranking	Split answer	New ranking	Area
Knowledge on how to relieve symptoms in regards to pain, dyspnoea, fatigue, xerostomia, obstipation, anxiety, depression, interaction between physical and existential symptoms, help to coping with cancer diseases. At the same time holistic thinking (hospice philosophy	1	Knowledge on how to relieve symptoms in regards to pain	1	Pain Management
		Knowledge on how to relieve symptoms in regards to dyspnoea, fatigue, xerostomia, obstipation	1	Symptom management
		Knowledge on how to relieve symptoms in regards to anxiety, depression, interaction between physical and existential symptoms, help to coping with cancer diseases.	1	Mental health issues
		At the same time holistic thinking (hospice philosophy)	1	Knowledge of palliative care
Knowledge on medicamental pain relief and how to administer medications.	3	Knowledge on medicamental pain relief and how to administer medications.	3	Pain Management
The difficult conversation. Openness towards death.	4	The difficult conversation. Openness towards death.	4	Interpersonal skills
The importance of interdisciplinary cooperation and how the different occupational groups can impact on dying patients.	2	The importance of interdisciplinary cooperation and how the different occupational groups can impact on dying patients.	2	Contextual conditions
Working with the relatives. How to help the relatives, during the patients disease and later. Also remember the children as relatives.	5	Working with the relatives. How to help the relatives, during the patients disease and later. Also remember the children as relatives.	5	Interpersonal skills

Appendix VI Overview of findings - nurses

No	Area	Subcategory	No. of respon-ses	No. sub-category	Ranked as nr. 1	Average	Standard deviation
1	**Interpersonal skills in relation to patients and their relatives**	Encounters with patients and their relatives – communication and interaction	118	76	24	2,84	1,4
		Personals qualities and experience		44			
2	**Symptom Management**	Knowledge	95	78	15	3,11	1,39
		Practical skills		17			
		Observational skills		4			
3	**Pain Management**	Theory on physiology and pain therapy in general	69	47	28	1,97	1,13
		Medicamental therapy		30			
		Non-medicamental therapy		7			
4	**Knowledge on palliative care**	What is paliative care?	29	20	9	2,76	1,46
		Hospice philosophy		5			
		Original		4			
5	**Contectual conditions**	Interdisciplinary cooperation	26	21	1	3,73	1,12
		Differences in cultural background		5			
6	**Mental health issues**	Handling grief	22	4	2	3,19	1,25
		Other emotional aspects of		8			
		The spiritual dimension		10			
7	**The concept of death**	Knowledge on the process of	13	10	2	3,17	1,53
		Practicalities concerning the deceased patient		3			

Appendix VII Overview of findings – students

No	Area	Subcategory	No. of respon-ses	No. Sub-category	Ranked as nr. 1	Average	Standard deviation
1	**Pain Management**	Theory on physiology and pain therapy in general	83	28	29	2,36	0,96
		Medicamental therapy		36			
		Non-medicamental therapy		10			
		Observational skills		7			
		Ethics		5			
2	**Interpersonal skills in relation to patients and their relatives**	Encounters with patients and their relatives – communication and interaction	61	39	15	2,60	1,33
		Personals qualities and experience		22			
3	**Knowledge on palliative care**	What is paliative care?	26	15	6	2,54	1,21
		Alternative medicine		6			
		Original diagnosis		5			
4	**Contectual conditions**	Interdisciplinary cooperation	26	7	3	3,42	1,41
		Legal issues		11			
		Organizing the environment		11			
		Timely issues		3			
5	**Symptom Management**	Knowledge	24	15	0	3,40	1,14
		Practical skills		8			
		Observational skills		1			
6	**The concept of death**	Knowledge on the process of dying	14	10	1	2,93	1,07
		Practicalities concerning the deceased patient		4			
7	**Mental health issues**	The spiritual dimension	13	2	3	2,77	1,36
		Handling grief		4			
		Quality of life		7			

Appendix VIII Overview of findings - teachers

No	Area	Subcategory	No. of respon-ses	No. sub-category	Ranked as nr. 1	Average	Standard deviation
1	**Interpersonal skills in relation to patients and their relatives**	Encounters with patients and their relatives – communication and interaction	24	12	6	2,75	1,33
		Personals qualities and experience		12			
2	**Symptom Management**	Knowledge	21	9	5	2,95	1,47
		Practical skills		6			
		Observational skills		6			
3	**Contectual conditions**	Interdisciplinary cooperation	8	4	0	3,5	1,31
		Legal issues		4			
4	**Mental health issues**	The spiritual dimension	5	2	0	3,4	0,89
		Quality of life		3			
5	**Knowledge on palliative care**		2		0	2	0